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ADVANCED NURSING PRACTICE for Older People

GUEST EDITORS: KAJA PÖLLUSTE, PIIRKKO ROUTASALO, LISBETH FÄGESTRÖM,
AND LIS WÄGNER





Advanced Nursing Practice for Older People

Nursing Research and Practice

Advanced Nursing Practice for Older People

Guest Editors: Kaja Põlluste, Pirkko Routasalo,
Lisbeth Fagerström, and Lis Wagner



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Editorial

Advanced Nursing Practice for Older People

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The world population is rapidly aging. Between 2000 and 2050, the proportion of the world's population over 60 years will double from about 11% to 22%. The absolute number of people aged 60 years and over is expected to increase from 605 million to 2 billion over the same period [1]. Although more developed countries have the oldest population profiles, the vast majority of older people—and the most rapidly aging populations—are in less developed countries. Between 2010 and 2050, the number of older people in less developed countries is projected to increase more than 250 percent, compared with a 71-percent increase in the developed countries [2].

Older people are considered one particular group of the population which needs and uses many health services of different nature, and the use of services is increasing with age. The aging of population has also resulted in increased interest in long-term care—in home care as well as in institutional care (residential and community care). The rising demand for long term-care is latest described in a three-year EU project titled INTERLINKS—health systems and long-term care for older people involving 13 countries in modelling INTERfaces and LINKS between prevention and rehabilitation to indicate new approaches and to improve policy and practice in long-term care [3]. To be responsive to the needs of older people, the continuity and quality of care should be improved by more effective management of care and improve the communication as well as interaction between patients, their family members, care providers, and politicians. It is important that the health services provided to

the older population be responsive not only to their physical but also to the mental and emotional needs. In this process the nurses have a remarkable role, which, however, sometimes may not be noted enough.

The papers published in this issue cover different fields of the organisation and content of nursing for older people from different parts of the world.

The provision of care for older people has undergone several changes and reforms to find best solutions and balance between existing resources and increasing demands. For example, S. Kato et al. propose models for designing long-term care service plans and care programs for older people in Japan; in the country, where more than 60% of population is aged over 60. One of the most important aspects for older persons is the independency of decision making for their future care and maintaining the autonomy, regardless of staying home with help from the municipality or moving to the nursing home. These aspects are discussed in three papers (A. Breitholtz et al., M. Riedl et al., and D. Goodridge). Also, some specific areas are presented as, for example, oral health care from the nursing perspective (K. Salamone et al.) and coping with the partner's health problems (S. Marnocha and M. Marnocha). Finally, besides those who receive the care, one may not forget the caregivers too. In this issue, two research papers from Scandinavia focus on the nurses and caregivers experiences and ethical values (M. Frilund et al. and S. Salin et al.).

We hope that this issue provides interest to broad audience not only for nursing professionals, but also for other

health and social care professionals while advanced nursing for older people like any other activity in health care can be most successful in team work.

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Research Article

Oral Care of Hospitalised Older Patients in the Acute Medical Setting

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Oral health care is an essential aspect of nursing care. There are many variances in the quality and frequency of the oral care that is delivered to patients by nursing staff, such as oral care being given a low priority when compared to other nursing care elements, oral care being neglected, and oral care delivery being dependent on the nurse's knowledge of oral hygiene. Additionally, there are some particular patient groups known to be at risk of oral health problems or who have existing oral diseases and conditions. As people age their susceptibility increases to chronic and life-threatening diseases, and they can be at increased risk of acute infections increases compromised by ageing immune systems. The aim of this literature review was to ignite the discussion related to the oral care practices of nurses for older acute medical hospitalised patients. The review revealed that nursing staff know that good nursing includes oral health care, but this knowledge does not always mean that oral health care is administered. Oral health care seems to be separated from other nursing activities and is not discussed when nursing care plans are written, only when oral problems are obvious.

1. Introduction

The aim of this review of the literature is to ignite the discussion related to the oral care practices of nurses for older acute medical hospitalised patients. This paper explores the literature related to oral health care for older patients admitted to acute medical wards. Caring for older patients with complex medical issues is challenging and one fundamental basic care is the provision of oral care which is often overlooked. Literature relevant to this issue was reviewed to confirm our view that oral care was often overlooked and could be improved.

As people age, their susceptibility to chronic and life-threatening diseases as well as acute infections increases, exacerbated by compromised immune systems. Tooth loss and periodontal disease are also prevalent in the older population [1]. The number of elderly people in society is increasing and consequently also the number of older people in need of health care and nursing care [2]. It is projected that by 2025,

the number of elderly people will increase by 146% to 1.25 billion worldwide [3]. Over the past two decades in Australia, the number of elderly people has increased by 170.6% [4]. The growth in this population of older people is staggering, posing tremendous challenges in caring for this group and their chronic conditions.

The consequences of chronic diseases and conditions are significant, leading to disabilities and reduced quality of life. Individuals with the most prevalent medical problems tend to have the highest rates of oral disease, with an association between poor oral health and adverse medical outcomes such as aspiration pneumonia and cardiovascular disease [5, 6]. Attention has been focused on oral care as the evidence accumulates to support an association between the bacteria in the mouth and those respiratory pathogens that cause pneumonia [7]. The benefits of this literature review can bring to light practice gaps, and areas for practice improvements for nursing care of this vulnerable group, through research, quality

improvement activities, and development of practice guidelines within a policy framework.

2. Literature Search

A search of the literature used the search terms *oral health* AND/OR *oral hygiene* AND *nursing* AND *medical patients* published between 2006 to 2012 in the databases of CINAHL and Medline. There were over 600 articles retrieved on oral hygiene/health; however there was limited literature that specifically focused on oral care for older medical patients in acute care. The literature in this review was obtained from nursing, medical, dental journals and government publications, and grey literature discussing oral care, hygiene, and inpatients. The literature excluded from this review was articles discussing oral health for children, and oral surgery.

3. Good Oral Health

Good oral health is important. Having a clean and healthy mouth contributes to a sense of well-being [8–11] allows for fluid and nutritional intake, assists with communication and quality of life [9], and assists with clear speech and communication [10]. Paulsson et al. [12] note that maintenance of good oral health is important for patients in hospital, as it contributes to the well-being, recovery, and nutritional needs of the patient, and it requires the involvement of nursing staff.

The literature suggests that oral care is not a highly technical skill or requires huge resources [9]. It is an individualised and practiced behaviour [13] and is an essential aspect of nursing care [9, 14, 15]. As Dickinson et al. [16] state, when a person is unable to perform their own oral care in hospital it becomes the responsibility of nursing staff. Bissett and Preshaw [8] suggest that oral care is like other personal care needs such as bathing and toileting; it is an essential component of holistic care [14]. There are variances in the quality and frequency of oral care delivery to patients. These variances in oral care relate to different factors, such as oral care being neglected [17–19] and oral care being given a low priority when compared to other nursing care elements [7, 8]. Oral care is dependent on the nurse's knowledge of oral care best practice. Fitzpatrick [20] acknowledges that nurses' knowledge of oral hygiene is variable. Oral hygiene is often thought to be underrecognised by nurses for the fundamental impact it can have on a person's wellbeing and health status [18]. In this context, poor knowledge has the potential to compromise the quality of patient care [21].

The delivery of oral care to hospitalised patients is recognised in the nursing literature as an imperative to maintaining health and wellbeing [22, 23] particularly in vulnerable groups of patients who cannot maintain their own oral health when hospitalised. There are some particular patient groups known to be at risk of oral health problems or who have existing oral diseases and conditions. These specific patient groups are cancer patients [24], palliative patients [13], patients who are intubated [17, 25], critically ill patients, frail patients [12], and the elderly [9, 26].

Research evidence suggests there are subgroups of older people known to be at risk of poor oral care, in particular people with dementia [27], and those that have come from residential care [20, 28–30]. It is often these subgroups of older people that are a majority of the patients on acute medical wards. Acute medical wards in hospitals are frequently filled with frail people, and this group of patients have been noted to often have comprised oral health (Andersson 1999 and Öhrn et al. 2001 as cited in Paulsson et al. [12]). Fitzpatrick [20] noted that older adults due to ageing processes have a loss of soft tissue attachments, which results in loosening of teeth root exposure, and teeth can become more brittle. Due to the ageing process older people have oral care needs that need to be met [26]. Common side effects of poor oral care are pain, difficulty with swallowing, poor or compromised nutritional intake [31], infection [26], systemic infection [23], and impaired communication.

4. General Medicine: Oral Health

In the acute medical setting, nursing staff are responsible for assisting with oral health care. Admission to hospital is not only a time for the active management of the presenting disease but also an excellent opportunity for the health promotion and screening for undetected pathology. Preston et al. [32] discuss the importance of nurses performing daily oral care for older people on acute, subacute, and rehabilitation wards; however these authors recognise that much of the nurses education in this important area has been provided during their early training and regular updates may not occur. The lack of knowledge about oral health care among nursing staff is also supported by Wårdh et al. [33].

Nursing staff know that good nursing includes oral health care, but this knowledge does not always mean that oral health care is administered [2, 32]. In a study that was conducted by Wårdh et al. [2] where 22 in-depth nursing interviews were administered, it was found that the quality of oral health care is largely dependent upon the cooperation of the elderly patients. Some nurses reacted in a negative way due to the risk of being bitten by elderly patients during oral health care. Patients who wore dentures were not always willing to take them out and cleaning dentures also seemed to be a repulsive activity. Some of the nursing staff in this study experienced a lack of time as a factor inhibiting good oral health care. Others did not see lack of time as a problem, but in stressful situations, oral health care could be easily forgotten. Ethical dilemmas can also become an issue. Some nursing staff worry about whether it is right or wrong to force oral health care when an elderly patient refuses care.

5. Implications for Nursing Care

Oral health care is an important part of treatment for all patients, particularly those who require assistance with activities of daily living. The majority of hospitalised patients within the acute medical units are older—over age 65 years [1]. Concerns regarding the nursing care older people receive in the acute care environment are frequently cited in

the literature and in particular the link between patient outcomes and nursing care. In this paper we have focused on oral care; however other aspects of patient care require similar attention but are beyond the scope of this paper. As the population ages, the likelihood of altered physical ability and presence of disease increases, leading to a reduced ability to perform activities of daily living, for example, oral care. Comorbid conditions most likely to be seen in the older population include, but are not limited to, diabetes, congestive heart failure, renal disease, glaucoma, and cataracts. These issues can lead to the need for hospitalisation often resulting in a protracted length of stay and the increased chance of deconditioning which in turn prevents older patients from attending to basic care needs such as oral care. Hospitalization can represent the beginning of functional decline and increased dependency that may lead to an individual requiring long-term care [34–37]. The state of a patient's oral health can have a significant impact on their health outcomes, most notably psychosocial well-being, respiratory health, and nutritional status.

Oral care is often overlooked in the context of acute medical wards within hospitals. Routine oral care (tooth brushing, mouth toilets, etc.) are often the responsibility of the nurse or health assistant without the required knowledge and skill or comprehensive hospital protocols to follow. This responsibility is related to decreased functional decline leading to ability to attend to ADLs. The link between functional decline and the need to assist with ADLs may not always be apparent to the nurses caring for hospitalised older patients. To overcome this issue the literature on this subject has identified the need for nurses to routinely assess oral health status and to determine what assistance is required for the patient to maintain good oral health, especially for older patients as debility and frailty can interfere with a patient's ability to self-manage their oral care.

Many patients are often admitted through the emergency department and as such may not come in with the basics—toothbrush and toothpaste. Nursing admission assessments do not routinely include assessment of the oral cavity or the patient's ability to manage self-care, and much of the assessment of oral care needs and self-care abilities of patients is subjective with decision support protocols not routinely available within the acute environment.

Anecdotal evidence suggests assessment of patient's oral health on medical in-patient wards is generally poor. Patient groups with specific needs often receive greater intervention with their oral care. Such interventions should be applied to all hospitalised patients. It is encouraging to note that the literature supports that when nurses are offered education and decision support they respond positively and actively engage [38–40].

6. Discussion/Conclusion

The available literature supports the view that oral health care of hospitalised patients is variable and overlooked and that nurses' knowledge and practice are variable. Nurses play a key role undertaking oral health care including the identification

and evidence to guide the patients at risk for therapy-related oral mucositis [41], periodontal disease (a chronic inflammatory condition), chronic infection of the tissue surrounding the teeth, and assessment of patients' ability to independently manage their oral hygiene. Fundamental to this assessment are both an oral assessment and a thorough functional assessment. This requires the involvement of the nursing staff, especially in cases where oral care and any necessary dental treatment are vital to ensure medical treatment.

In the acute medical setting, oral health care seems to be separated from other nursing activities and is not discussed when nursing care plans are written, only when oral problems are obvious. To enhance the integration of oral care within routine nursing practice using a patient centred approach, some strategies may include education of staff, patient, and carers; provision and/or increased accessibility of equipment (toothbrush, toothpaste, and mouth wash); and inclusion of oral health care as a major component of all documentation of nursing care [2]. Policies and practices that support the maintenance of good oral health are needed to lessen the disease burden and promote healthful aging for this growing population [42]. Health care professionals need to reduce the obvious service fragmentation and collaborate, especially since the most severe oral problems are usually found in the older patients [1].

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Research Article

Being a Nursing Home Resident: A Challenge to One's Identity

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Going into a nursing home can turn out to be a critical life experience if elderly people are afraid of losing their independence and identity after having moved into a nursing home. In order to find out what nursing home residents need in their first year after having moved into a nursing home to maintain their identity and self-determination, 20 problem-orientated interviews with residents of three nursing homes in the Austrian province of Salzburg were conducted and analysed based on content analysis according to Mayring. The participants of this study resist against having decisions taken away from them and fight for their independence and identity. In order to be able to cope with these strains, they need the help of family members, professionals, and identity-forming conversations in new social networks in the nursing home. The study participants draw enough strength from their faith in order to fight for their independence. They develop a new identity close to their previous identity by maintaining autonomy and mobility with a clear focus on the future.

1. Introduction

Currently, 16% of the entire European population are 65 years of age or older. From a demographic point of view, the European population is “twice as old” as the world population, whose proportion of senior citizens is 7%. According to forecasts, the proportion of senior citizens will reach 28% in 2050 [1].

Ageing from 75 years and onwards is characterized by critical changes and turning points, such as the death of a partner or a child, increasing health problems, the increasing need for care and possibly the move into an old peoples home or a nursing home [2].

In order to assess the current state of knowledge about the changes which the elderly experience in their first year after having moved into a nursing home, systematic literature research on “what changes do nursing home residents experience after their move into a nursing home?” was conducted [3]. Publications both in English and German, published between 1996 and 2010, were used. The following databases were utilised: Cinahl (Ebsco), Academic Search Elite (Ebsco), PsychInfo, Medline (PubMed), Embase, DIMDI, Gerolit, WISE, Cochrane, and Ageline. Keywords used are residential

home/nursing home, home admission/moving into a nursing home, institutionalization, and burden.

People who move into a nursing home experience different types of changes which they feel to a greater or lesser degree is stressful. The change in social status, the impact on autonomy, the feeling of having no place to call home, the change in social contacts, and the reduction of habitual activities rank first in the presentation of the results and endanger the people's identity which they had before [4]. Moving into a nursing home is an individual experience [4]; the adaptation time frame is between 3 and 6 months [5, 6].

The experience in the nursing home is accompanied by a fight for autonomy and against having decisions made for them and actions imposed [7, 8]. Nursing home residents have experiences which they perceive as compulsive and degrading. They have to obey the staff in order to get on with them [9].

People living in a nursing home consider their self-determination at risk because they feel dependent on the daily nursing care process. Waiting for help and support is experienced as a feeling of powerlessness [10]. In addition, the nursing home residents experience a feeling of having no place to call home, as there are no private rooms available

in nursing homes [11]. The boundaries between public and private spheres in the nursing home are seen as blurred in contrast to the clear boundaries that characterize the domestic home [12].

Social contacts are perceived differently after entering a nursing home than they were before. Nursing home residents still want to feel part of society outside the nursing home [10]. They also wish to remain in contact with family members and friends, thereby maintaining their social contacts from earlier times. This maintenance of earlier contacts demonstrates appreciation and respect for people living in a nursing home. It is sad to note, however, that contact between many nursing home residents and their families becomes rare after they move into a nursing home. The stated reason for this is a combination of lack of interest, a general avoidance of topics of disease, and homes for the elderly on the part of the family [7].

Lee [13] confirms that nursing home residents often advise their family members against visiting them because they do not want their family members to see life in a nursing home. The residents see their own dignity at risk because they are confronted daily with the increasing need for care, and support of the other residents [14]. In principle the dignity of nursing home residents appears to be based on social relationships [14], but it is actually the establishment of relationships among the nursing home residents which presents a particular challenge [7, 12, 13]. Nursing home residents require the support of staff when establishing interpersonal contacts, but their experience is that such support is inadequate. The nursing home residents experience the staff as people who are primarily responsible for maintaining order and discipline and spend their time dealing mainly with administrative tasks [13]. As a result the residents keep themselves to themselves and describe other residents as unfriendly and inactive. They make statements of feelings of dislike and repulsion towards their fellow residents [7].

According to Mateos et al. [15], nursing home residents complain that independence within the nursing home is given little attention. The motives of the elderly for staying active are insufficiently taken into account. Dependent behaviour is rewarded by the staff more than independent behaviour. The residents therefore hardly make use of their own capabilities because they feel that their abilities will be insufficiently recognised. Kane et al. [16] demonstrate that nursing home residents want to decide for themselves on that daily support which they receive in order to maintain their independence.

According to Petzold [17], there is not enough time for fostering the competences of nursing home residents. Moreover, Petzold describes an overcompliance by nursing home residents. They do not protest, they display a high degree of subordination, they try to pander to all levels of staff in the home, and thereby they contribute to the progressive dismantling of their own competences. As a result the level of care needs increases, mental and psychosomatic disorders occur, nursing home residents socially withdraw, and they begin to lose their identity.

Therefore entry into a nursing home constitutes a momentous and significant event and turning point in the

lives of the elderly. In fact, an ever shortening life span of residents after their entry into the nursing home is noticeable. 22% of residents die within the first six months of being in a nursing home [18].

1.1. Research Question. What is the experience of nursing home residents during their first year in the nursing home and how can they maintain independence and establish a social identity within the home?

In order to find the answer to this research question, a qualitative study [19] was conducted with nursing home residents in three nursing homes and homes for the elderly in the Austrian province of Salzburg.

2. Framework

To handle the concept of identity, the Identity Theory of Petzold [20–22] was chosen. Petzold [21] defines identity as the result of ego's synthesis performance in the processing of mutual (reciprocal) identifications from diverse social and cultural contexts (foreign attributions, foreign images), their emotional evaluation, the cognitive assessment and their connection with identifications (self-attributions, self-images). Petzold [20] also describes identity as the "answer to the questions "Who am I?" and "Who do I belong to?"

"Identity is what a human being gains by recognising himself through real perception and acting as the one he is (self-identification) and by being recognised by his fellow beings within his relevant environment as the one they see in him (identification from outside)" [22]. A human being's personality develops through social relationships. This means that identity develops via a process of social experiences, activities, stories, and dialogues with other people. Life situations and conversational partners change throughout the course of life, and therefore identity is to be seen as a constantly changing process. The formation of identity never ends [20].

Identity is subject to more or less considerable changes throughout the course of an individual's life. These changes include the alteration of living environment and bodily changes, particularly those due to age [22]. Elderly people like telling stories from former times again and again because they live in a world of memories from the past. Reminiscing and being in a state of thinking and reflecting means that contents of the long-term memory will emerge. These stories which stabilize identity are important as the elderly generate their sense of living from their reflection of the past [20].

Each story and all identity-forming elements of a story undergo "cerebral and mental processing," which provokes a changeable identity in human beings. Therefore identity can be seen as a process that never ends and is constantly changing [21].

A human being's personality develops and grows in social relationships and includes five core areas (body; social relationships; work/performance/free time; material securities; values) from which a human being's identity is formed.

Identity-forming stories take place in the five essential identity areas that are described in the following. In these

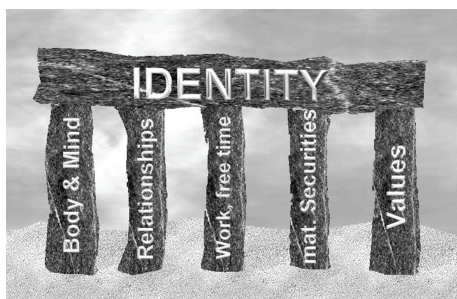


FIGURE 1: Five pillars of identity by Petzold (own drawing).



FIGURE 2: Broken pillars of identity (own drawing).

identity areas, one's own important individual experiences are shared with other people. These shared experiences of the people who tell the stories mutually influence their identities for the future. Metaphorically speaking, the five identity areas are called “pillars” (Figure 1) on which a human being's identity is based. The identity areas merge, and one area influences the other. The pillars are to be seen in a gender-specific manner [20–22].

According to Petzold [20], the level of strains placed on the identity of seniors is very high due to negative attributions and social deprivation. The ego no longer manages to perform synthesis. The ego weakens and is no longer able to stabilize a clear identity. If the social identity weakens at the same time, then a positive identification will be missing.

The identity is breaking down (Figure 2). The affected nursing home residents show a deterioration in performance, emotional exhaustion, crises of self-worth, and mental symptoms, such as aggressiveness and social withdrawal [20].

In order to gain information on how the elderly experience changes to their identity in the first year after having moved into a nursing home, a qualitative study was conducted in Austria.

3. Methodology

The study was comprised of residents ($n = 20$) from three nursing homes in the Austrian province of Salzburg. The criteria for inclusion in this sample were stays in a nursing home of less than one year, being more than 70 years old, physical and mental stability, not bed-ridden, cognitive ability to answer questions, competence to process

information on the research subject, and no diagnosis of dementia. No sample size was determined in advance.

The access to the research field was gained by the first author, through contacts to the management of the nursing service of three nursing homes.

The recommendations of Burns and Grove [23] with regards to the “informed consent” were implemented: study participants were informed about the aims of the study and the protection of personal data; the outcomes of the interviews were exclusively used for this study; the participants can revoke their consent at any time. The exposé was examined by an ethics committee; the committee confirmed the compliance with ethical principles.

The data was collected through problem-orientated interviews according to Witzel [24]. The interviewee is seen as an expert on his own opinions and actions. The interviewer asks questions in order to generate narrations, alternating with questions in order to generate understanding. In order to facilitate the implementation of the interviews, short questionnaires, guidelines, a recording device, and postscripts are used.

The basis for the guidelines was due to the result of the literature research on the identity theory of Petzold [20–22, 25]. The semi-structured guidelines were divided into questions on their current life situation, review of the past, change of identity caused by moving away from home and into a nursing home, social contacts in the nursing home, and questions on expectations and wishes for the future.

Before it was applied, the guidelines were tested in a test interview with a female nursing home resident who had fulfilled the inclusion criteria and were then modified accordingly. Some extensive questions were split into two or more questions. The result of the test interview was not included in the analysis.

The interview was conducted with open questions in order to give the study participants space and time to talk about their experiences. All the study participants were asked all of the questions. However, the order of the questions was adapted to the progression of the interview.

The interviews were conducted by the first author of the study in the study participants' individual room. They were also conducted without a third party being present.

After each interview, the results were summarized then communicated, and discussed with the interviewee. The key aspects were documented in the interview record, and the results were approved by the study participants.

The interviews were analyzed following the transcription rules for computer-assisted analysis according to Kuckartz [26] in a slightly altered form; the study participants spoke a dialect, and therefore the texts of the interviews were polished. The records of the interviews with the study participants were then imported into the text memos of the MAXQDA program [26].

The data was analyzed by means of the MAXQDA program [26] and was based on summarizing qualitative content analysis according to Mayring [27] following the nine-step process model (Figure 3) (material collection, descriptive analysis of the development situation, formal features of the material, trend of the analysis, theory-driven

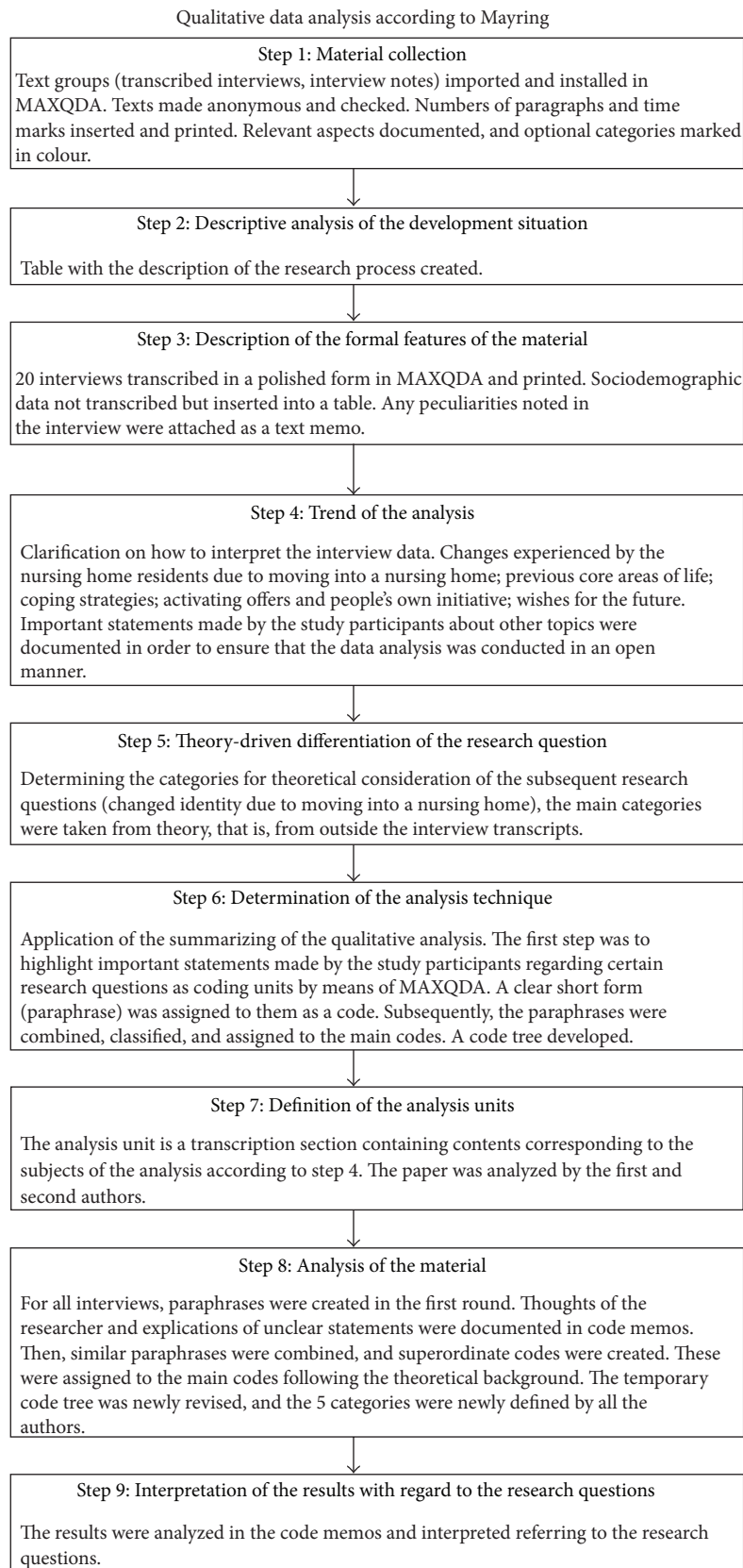


FIGURE 3: Process model of the qualitative data analysis (illustration compiled by the author).

differentiation of the research question, determination of the analysis technique, definition of the analysis unit, analysis of the material, and interpretation of the results with regard to the research questions). The results were analyzed by the first and second authors of this paper [19] in order to gain a joint agreement on the final results.

The quality criteria of qualitative research [23] were met as follows:

- (i) detailed processing of documentation—see Figure 3;
- (ii) safeguarding interpretations with arguments—see step 7;
- (iii) research process structured by rules of conduct—see step 6;
- (iv) closeness to the study participant—the interviews were conducted in the residents' bedrooms;
- (v) communicative validation—after each interview, the results were summarized, communicated, and discussed with the participants; the results were then approved by the study participants.

3.1. Results of the Study. All interviews were conducted in July and August, in the year 2010. The study participants were aged between 71 and 93 (average = 82.35 years). The duration of the interviews was between 16 and 78 minutes (average = 35.5 minutes). The length of stay of the questioned nursing home residents was between 2 and 11 months (average = 7.2 months) at the time that the interview was conducted.

After a total of 20 interviews (15 women, 5 men) had been conducted, no new findings were evident from the authors' point of view with regard to the research question and aims. Hence, theoretical saturation had been reached.

The core messages of the interviews were represented by means of a category system. Five core categories were derived from the data material.

3.1.1. Category 1: Experienced Changes—Demands on Identity. When nursing home residents move into a nursing home, they have an emotionally stressful time, and they feel left alone and realise that their previous core areas of life are changing considerably. As they move into the nursing home, they find themselves in a state of shock, which is often accompanied with tears as it dawns on them that they are losing their home. "Here, I realise that I do not have a home anymore" (B2, 18-18) "Now, that I have been institutionalized in the nursing home, everything is gone." (B2, 105) "Here, you are in a waiting room for death." (B3, 98) "This is a new phase, tears are falling." (B2, 98) [19].

The conditions of the fellow residents puts a strain on the study participants. "When I had to pass people who I had known in younger days when they had been healthy and when I saw the condition they were now in, I was very shocked." "One often thinks how pitiful people may become, first of all mentally." (J1, 17-18).

Due to having to go into a nursing home, identity-shaping core areas of life will change. The study participants feel exposed to a strongly reduced financial situation. "One is a

hardship case" (J8, 49). "My friend said: Do not move into a nursing home. They will take all your money there." (J2, 75) [19].

The loss of previous work gives the nursing home residents the feeling of being nothing and a nobody. "It's a new situation if one moves into a nursing home. At home, I used to cook for my children and grandchildren. There I had a task to fulfill." (S1, 90) "Moreover, I still used to sew and knit everything for the kids myself." (J1, 26). "But here, nobody mentions that anymore." (J8, 15) [19].

The study participants, who experienced the process of moving into a nursing home positively, highlight the advantages of living in a nursing home. "Here, I have someone to talk to. At home, I used to be alone because my daughter works" (J9, 33-34) [19].

3.1.2. Category 2: Coping with Changes. The process of moving from one's own flat into a nursing home is handled very differently by each study participant. In the adaptation phase, nursing home residents talk to others about their feelings, such as sorrow and home sickness. Some study participants cope throughout the arrival period with comforting prayers. "I draw strength from praying, I consult with Mother Mary" (J9, 95).

Visits to the cemetery are described as very comforting by several of the study participants and help them cope better with what they experience. "I often visit the grave of my parents-in-law. I take care of the flowers and talk about my worries at the grave side" (J8, 95) [19]. In the interviews, the nursing home residents repeatedly pointed out that they found comfort in faith. "Yes, I am indeed a believer. I pray often. Yes, now I have time for it. Yes, thus I can cope better with it. Faith gives me support. Yes, you can take your faith with you to the nursing home" (S2, 142, 162) [19].

Some study participants overcome their grief by talking about it to others. "I also have bad times, indeed. Last time I told my GP that I have a feeling like homesickness. It is a feeling of longing for something. You are full of thoughts. And this makes you sad. I also talk about it with my children. They acknowledge that they had a loving childhood home. This makes me feel relieved." (J1, 33) "This is not really my home. When they pick me up and take me back, I always think to myself: Here, I am not at home." (J6, 38). "However, I understand that this is the only solution. At the age of almost 90 one must be happy about this situation." (J6, 40). "Of course, moving into a nursing home was a shock for a bit. One has to chat with the other nursing home residents, then it is actually quite ok." (S1, 44-46).

One female study participant regularly talks about her grief to her teddy bear which she took with her from home because she does not want to be a strain on her children. "Yes, and the teddy. . . I always have him with me. I need him to sleep. I took him with me from home. I talk to him, I tell him everything. He sleeps in my bed. There, I talk to him." (S1, 135).

Some of the residents questioned are still struggling to overcome their grief. "I will have to put up with it. At the moment, it's better. I was crying a lot. I talked about it with my doctor, and then he prescribed some medication for my nerves.

It has got better" (J7, 52-54). "To be honest, if it was possible, I would love to die immediately" (B7, 102).

Some nursing home residents cope with the situation positively by highlighting the advantages of living in a nursing home; for example, help is available all around the clock. *"I prefer living in a nursing home. Yes, because here I know all the nurses. I just have to push the button and a nurse comes at once" (B5, 41).*

3.1.3. Category 3: Maintenance of Autonomy through Mobility. According to Kruse and Wahl (2010) the concept of health in old age focuses on the ability to lead an autonomous and independent life despite having an illness. In this context, the individually chosen and adopted strategies to find meaningful activities are important [28].

The study participants, more often than not, downplay the offers made by the nurses to support them in the handling of their physical deficits. They refuse to believe in their shortcomings and say that they can do everything themselves, apart from cleaning and cooking. It is to be noted that the participants of this study ensure that they themselves stay mobile and independent by taking walks to the cemetery and to their former living areas, as well as by taking trips and train and bus excursions. In particular, it is highlighted how important it is to have the opportunity to leave the nursing home without any nursing home employees at any given time. This possibility gives the nursing home residents a feeling of freedom. *"We, the women of the nursing home, go for a walk almost every day. Yes, once a week I visit my cat at my old house. Then I pet her and say: "My beloved Cindy." What a pity. But she wants for nothing." (J4, 84, 28) "I do not have any relations in the nursing home. No, I do not have any. I often go for a walk, go shopping or stroll along the river. I know some of the people who walk there. That is all I have." (S4, 162). "Sometimes I go to friends by bus because I have a senior citizen's ticket. In the evening I go back again to the nursing home" (J2, 57) [19].*

For one study participant it is of particular importance to have a key and thus the possibility to leave the nursing home at any time. *"Mostly, I do not attend the in-house dinner. At dinner time I drive around the village center in my wheelchair with some friends of mine. I tell a member of staff when I leave the nursing home. This is not a problem. Sometimes I am not back before midnight. I have a key. So, I can come and go whenever I want. That's great. Because the staff do not have to give a key to the residents." (B1, 6).*

3.1.4. Category 4: Establishment of a New Identity by Creating a "New" Normality. In the present study, the participants compared normality in the nursing home with their life situation at home, before they moved to the nursing home.

Elderly people who are moving into a nursing home try to keep as many of their habits as possible from the good old days. The new normality is adapted as closely as possible to their previous life. When this new normality has been accepted, this new place of living can then be seen as home. Nursing home residents try to reestablish "normality" by arranging their new room accordingly, for example, using the furniture from their previous home. These objects from the good old times, when the study participants were younger,

shape their identity and provoke positive memories. *"My GP said: "your place in the nursing home is like it used to be in your old home". At home, my photos were also placed right above the sitting corner, just like they are here in the nursing home" (J1, 23) [19].*

The study participants wish to partake in activities in the nursing home that are comparable to their previous hobbies and roles in life. The activities serve to keep the residents occupied, but also to stabilise their identity. Activities give the study participants a good feeling of being useful. *"I have my Hoover with me and Hoover my room. The children take their shoes off when they come in. I make the bed myself. Yes, that's quite nice. I am satisfied" (B2, 65, 67) "I live with the flowers. I have already done something, have a look. Carnations, I look after them. I water them and cut them" (J8, 44).*

In the interviews, the nursing home residents who were questioned repeatedly pointed out that they found comfort in faith. *"Yes, I am indeed a believer. I pray often. Yes, now I have time for it. Yes, thus I can better cope with it. Faith gives me support" (S2, 142, 162) [19].*

The study participants partly reject social activities that are offered to them by the employees of the nursing homes. They complain about conflicts amongst the residents and therefore keep out of one another's way. *"Yes, there is always one person who is jealous of everyone. I get the pullovers from my sister, they envy me, and also my bedroom. I simply avoid these people" (S4, 78) [19].*

3.1.5. Category 5: Wishes and Expectations for the Future. The new nursing home residents feel healthy and wish that their physical state will not change. *"I have no expectations anymore. I want to stay healthy and then die quickly" (J1, 59) [19].*

Some study participants express fear of becoming a person in need of care. *"I have no expectations anymore. The principal thing is not to become a nursing case. I do not want to become an invalid as some of the other residents. I do not want to lose my mind. In this case, I would rather die" (J1, 59).*

The elderly are realistic when it comes to the end of life. *"It is sad. One should not become that old. If it was possible, I would like to die, yes." (B7, 130) "In the past, I was very afraid of death. And now I think it is pleasant. I sometimes even look forward to dying" (B9, 59).*

Some study participants express the longing for death; they actually wish to die. *"Dying would be alright with me at any hour before I have to suffer, as I can see so many here do. Then I think to myself that I want to fade away now. One is always confronted with sorrow, with so many images of bad conditions" (B2, 53-54) [19].*

The participants of this study are glad to have arranged everything in the case of their death. *"Yes, I wish to have a nice place in my husband's and son's grave. After my son died, we bought a grave in a place where a tree had been before. We selected this place. There is a place left for me which is as beautiful" (J5, 145) [19].*

4. Discussion

According to Riedl et al. [3], the elderly's experience of moving into a nursing home is unique to each and a critical

moment in their life. Despite preparation for this critical moment, the move into a nursing home causes change in social status, impact on autonomy, the feeling of having no place to call home, change in social contacts, and the reduction of habitual activities all of which up until this point has formed this persons' identity. In the adaptation phase during the first half year in the nursing home, many of the residents feel over-challenged and unable to cope with the new situation. The other residents are perceived as a strain, and the nursing staff are seen as the ones responsible for upholding discipline and order with little time for supporting new residents. The nursing home residents miss a private space which should be their new home. In this period, the identity of the elderly is endangered and threatens to break down [3].

For the participants of this qualitative study from Austria, "the experienced changes" were a great challenge to the identity's lived up until this point. On the one hand several pillars of identity were weakened by emotional pressures such as homesickness, perceived changes in the main focus of their lives, and the changed financial situation. On the other hand, the participants of this study showed that they still possessed enough emotional resources to view the move into the nursing home as reasonable after a few months. They carefully select residents as conversation partners who do not cause emotional strain through their need for care. The willingness to talk to others instead of withdrawing helps establish their future identity [21]. Nursing home residents who's condition is perceived as being emotionally stressful either by confusion or a high level of physical care will be avoided as conversation partners. According to Petzold, identity is the "answer to the questions "Who am I?" and "Who do I belong to?" [25] and thus can be seen as the reason for the rejection of communication with confused residents.

Similarly as in the study of Hanisch-Berndt and Göritz [29], nursing home residents choose a strategy of rejection in order to maintain a self-image that is as positive as possible. The participants of this study confirmed the importance of a positive self-image by describing the physical support given by the nursing staff as completely insignificant. In the interviews, support by the nursing staff was only mentioned in the context of household activities, such as washing clothes and cleaning the floor. In doing so, the participants of this study confirm Pleschberger's work [14] which supports the view that nursing home residents see their dignity in danger when confronted by an increasing care requirement for themselves. Financial concerns correspond with the studies of Kane et al. [16]. The nursing home residents strive to have money of their own. This brings a degree of independence, creates a desired freedom, and strengthens the pillar "material security" [20].

As stated in the study by Heliker and Scholler-Jaquisch, the study participants seek out people with whom they can discuss and share their problems with in order to "cope with the experienced changes positively" [11]. According to Petzold [25], genuine personal encounters are possible when the nursing home residents exchange their experiences with each other. New social spheres develop through common experiences, and the pillar of "social relationships" is

stabilized. Thus, the first steps towards settling into the new home environment have been taken. In addition sharing one's own stories with the nursing staff is important in order to get to know one another. According to Pleschberger [14], nursing home residents dignify themselves not only by their behaviour with other residents and nursing staff but also through what they have achieved during their lifetime. Moreover, the study participants can work on maintaining their own mobility and autonomy by not requesting more help than is necessary from the nursing staff and thus considerably strengthen the pillar of "physical well being."

Religious rituals, such as pray and regular visits to the graves of deceased family members, help the study participants cope with their entry into the nursing home. People will be identified in their environment and chosen as new friends, if they show a similar attitude to that which they exhibited prior to entering the home. The "pillar of values" is strengthened. The study participants ensure for themselves, through their means of coping that their changed identity remains stable and that communication with social support networks continues.

Striving for "maintenance of autonomy through mobility" is constantly highlighted throughout this study. As also stated in the literature of Kruse and Wahl [28], the concept of health in old age focuses on the ability to lead an autonomous and independent life despite any illnesses. In this context, the individually chosen and adopted strategies to find meaningful activities are important. The participants of this study say that they do not suffer from physical deficits. They do this in order to avoid being at the risk of being someone who is regarded as in need of support and of having everyday life in the nursing home organised for them by the nursing staff. The freedom to decide when you leave the nursing home and with whom ties in with the importance of maintaining the previous identity. The institution's impenetrable boundaries as described by Gamliel [30] are thus removed.

The physical care as mentioned by Koppitz [10] is accepted at both the beginning and end of the day, but during the day the study participants strive for autonomy. Through their own initiative, they are active and plan their everyday life themselves. In doing so, the study participants have the feeling of personal integrity, self-assertiveness and have the personal freedom in which to decide how to spend their time. Former preferences may even be reactivated. Thereby the participants of this study seem largely satisfied with their life in the nursing home. As stated by Mateos et al., they stay active in order to be able to take part in the activities which are meaningful to them [15]. The nursing staff at the Austrian nursing homes, who was chosen for this sample study, does provide the required social support [8]. This is done by not preventing the study participants from performing their planned activities.

If mobility and autonomy are preserved to a sufficient extent, the study participants start the "development of a new identity and the establishment of a "new" normality." Memories are kept alive in their room in the nursing home through the furniture and objects which they brought with them and thus inspires them to tell stories from earlier times. Photos, crockery, items of clothing, and so forth

strengthen their previous identity. Activities, which can no longer be performed due to being in a nursing home, such as running the household, are upheld through stories, giving these memories a positive tinge. As in Petzold's study [25], the participants also generate their sense of life through reflecting the past.

The study participants tell their stories and exchange their experiences every day. As confirmed by Breyll [7], this is the way in which they tie in their previous life outside of the nursing home. For example, this is how female study participants who themselves have raised children can continue their role as a mother through their stories. As described by Heliker and Scholler-Jaquish [11], stories that are told which people have in common, manifest interest. Just as the people questioned in this study make new friends in the nursing home through the stories they share with each other. The study participants take several core areas of their lives into the nursing home with them, such as religious rituals and knowledge from their previous everyday life.

They can continue to pursue their hobbies in the nursing home or aspire to taking up a new hobby. One study participant, for example, enjoys doing handicrafts and confesses to having never had time for handicrafts before. As proved by Lee [13], the participants of this study also make an effort to reestablish their new identity and their "new" normality as closely as possible to their previous life. The study participants manage to define clear boundaries, and according to Hauge and Heggen [12] clear boundaries characterize life at home. After they have succeeded in stabilizing the pillars of their identity, even though they have moved into a nursing home, the study participants live their new identity as nursing home residents in a largely self-confident and satisfied manner after a relatively short period of time.

This fact underlines changeable identity as described by Petzold [22], which according to the results of this study can also be coped positively by the elderly (average = 82.35 years).

The "wishes and expectations" of the study participants are congruent with the remarks of Mahs [31]. The participants of this study wish their families to be well and to stay healthy themselves. They rate their health status as good and hope for many more healthy years. However, they are afraid of becoming an invalid beforehand.

The study participants are not afraid of dying. They know that death is a part of life. They have made all the preparations in the case of their death. Kruse [32] confirms this fact by stating that the preparation for death is a borderline situation which makes people grow and develop. According to Kruse, elderly people have the feeling that death occurs at the right point of time in old age.

Similar to the study of Mahs [31], the people questioned in this study also believe in resurrection. According to the results of this study, they find comfort and hope in faith and draw strength from it, as Petzold described, for their life in the nursing home [22]. From the stated wishes and expectations, the conclusion can be drawn that most of the formulated wishes do refer to their own death, but that the people questioned are satisfied with their situation in the nursing home, and that they have managed to establish a

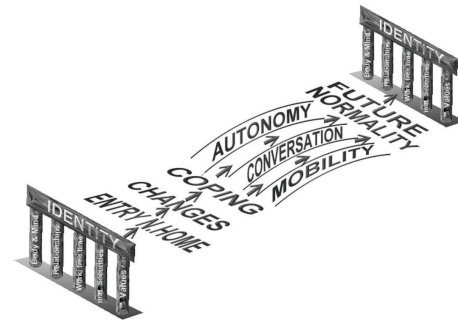


FIGURE 4: Entry into a nursing home and future identity (own drawing).

"new" identity which gives them hope for a good and positive future.

5. Conclusions

On the one hand, the results of this study show that moving into a nursing home is a critical life experience, but on the other hand, elderly people manage to cope with this move and can create an identity for their future. In order to be able to cope with the demand on their identity, they need identity-forming conversations in new social networks in the nursing home as well as the support from their family members and professional helpers.

Figure 4 is an attempt to represent the path to a changed identity as a nursing home resident. The identity of the elderly is based on their entire previous life. Moving into a nursing home destabilizes the identity that had been lived up to that point in time. The first challenge which the affected people face is coping with the psychophysical and social changes [3].

Every change that is accepted leads to an adaptation to the new situation. Another task in the adaptation process is to maintain autonomy and mobility in order to be able to take part in decision making and to experience a positive self-image. In doing so, progressive degeneration of competences in the elderly people can be counteracted [19, 32].

Identity is also changeable in old age and can live up to the demands of moving into a nursing home. The new identity is formed on a mutual basis through intersubjective interaction with different people in social networks. A common bond develops by telling identity-forming stories. If this happens, nursing home residents can build a normality close to their previous normality. A stable, changed identity (Figure 4) develops. Nursing home residents take part in the decision making processes regarding life in the nursing home and thereby remain future orientated.

6. Implications for Practice and Research

From the results of this study, recommendations on how to act when somebody moves into a nursing home and on the adaptation phase of the elderly within the nursing home can be deduced. Elderly residents need to be supported by their participation in decision making when selecting a

nursing home, by determining the time of the entry into the nursing home, by the maintenance of a support network in and outside the nursing home, by involvement in financial matters, and by the maintenance of mobility and autonomy. A narrative climate should be established in order to make identity-forming story telling possible.

In order to be able to give nursing staff and those with political responsibility reliable recommendations for action, further quantitative, and qualitative studies are required. The results of this study provide ideas for those areas in which further measures can be developed.

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Research Article

Planning for Serious Illness amongst Community-Dwelling Older Adults

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Older adults have long been encouraged to maintain their autonomy by expressing their wishes for health care before they become too ill to meaningfully participate in decision making. This study explored the manner in which community-dwelling adults aged 55 and older plan for serious illness. An online survey was conducted within the province of Saskatchewan, Canada, with 283 adults ranging in age from 55 to 88 years. Planning for future medical care was important for the majority (78.4%) of respondents, although only 25.4% possessed a written advance care plan and 41.5% had designated a substitute decision maker. Sixty percent of respondents reported conversations about their treatment wishes; nearly half had discussed unacceptable states of health. Associations between key predictor variables and planning behaviors (discussions about treatment wishes or unacceptable states of health; designation of a substitute decision maker; preparation of a written advance care plan) were assessed using binary logistic regression. After controlling for all predictor variables, self-reported knowledge about advance care planning was the key variable significantly associated with all four planning behaviors. The efforts of nurses to educate older adults regarding the process of advance care planning can play an important role in enhancing autonomy.

1. Introduction

Given that almost three quarters of older adults lack decision-making capacity when urgent choices about life-sustaining treatment need to be made [1], older adults have long been encouraged by nurses and other health care providers to express their wishes for health care while they are healthy enough to meaningfully participate in treatment decision-making. Advance care planning has been recently promoted by the Centers for Disease Control and Prevention [2] as a process contributing to overall public health through its focus on supporting the individuals' health care choices and preventing unnecessary suffering. Widespread social marketing of advance care planning has made many excellent online and print resources available to the public [2–4].

Although advance care planning is now seen as an iterative process that includes the way in which people think about and communicate their values and preferences so that they may receive the health care they desire in the case of life-threatening illness [5], much of the extant research

in this area has focused upon the completion of written advance care plans. Using a population-based approach, this study addressed the research question “How do community-dwelling adults aged 55 years and older plan for serious illness, either formally (e.g., by designating a substitute decision maker and preparing written advance care plans) or informally (e.g., by discussing states of health considered to be unacceptable to continue living or desired medical care in the event of serious illness)?” The overall objective of this study was to identify the associations between formal and informal planning for serious illness and key sociodemographic, health, and knowledge variables. Based on a review of current literature on advance care planning, it was hypothesized that sociodemographic variables (including age, gender, urban or rural location, education level, and income level), values (importance of planning for future care), and self-reported knowledge of advance care planning would be statistically significant predictors of behaviors relating to planning for serious illness.

It is estimated that between 18% and 36% of all American adults in the general public have completed an advance directive [6]. Rates of advance directive completion amongst distinct subpopulations, such as persons with terminal illnesses and older adults, have been reported to range from 15% to 84.9% [1, 7–13]. Completion of an advance directive is associated with a wide range of factors, including “older age, greater disease burden, type and acuity of condition, White race, higher socioeconomic status, knowledge about advance directives or end-of-life treatment options, a positive attitude toward end-of-life discussions, a long-standing relationship with a primary care physician, and whether the patient’s primary care physician has an advance directive” [6].

While the clinical utility of advance directives has been rightfully questioned [14–20] and the uptake by intended consumers less than hoped in spite of widely available resources, support for the overall process of people considering and sharing key values and preferences for health care in the face of serious illness remains strong [5]. Social marketing campaigns have increasingly focused public attention on promoting dialogue, rather than completing forms, as a means of supporting the preferences and autonomy of individuals who may not be able to communicate his or her wishes for care in the future.

A number of studies have examined the extent to which discussions related to advance care planning are taking place, as well as the outcomes of these dialogues. Between 75% and 91% of participants over age 65 in the Canadian Study of Health and Aging [21] had considered who might make health decisions for them if they were unable to do this for themselves. The same study revealed that between 46% and 69% had discussed their preferences for end-of-life care with someone else. The benefits of having discussed preferences for future care were noted in a study of patients with advanced cancer by Wright and colleagues [22] and encompassed less aggressive medical care, including lower rates of ventilation (adjusted OR 0.26; 95% CI 0.08–0.83), resuscitation (adjusted OR 0.16 95% CI 0.03–0.80), ICU admission (adjusted OR 0.35; 95% CI 0.14–0.90), and earlier hospice admission (adjusted OR 3.37 95% CI 1.12–10.13), as well as better patient quality of life and improved bereavement adjustment. Discussions early in the trajectory of cancer have also recently been demonstrated to be associated with less aggressive treatment and greater use of hospice care [23].

Despite these positive outcomes, many people remain skeptical about the benefits of advance care planning, fuelled in part by society’s denial of the inevitability of death [24, 25] and death’s “sequestration” from mainstream society [26]. The choice *not* to engage in advance care planning is complex and highly individual but may include any one or more of the following reasons: believing that one’s health is good and it is not necessary; believing that advance care planning is only for the terminally ill, elderly, or infirm; challenges discussing death; not being “ready”; lack of knowledge; difficulty completing the form; reluctance to broach the subject with the physician; fear of being a burden; incompatibility with cultural and spiritual traditions; preference to delegate treatment decision-making to family or others; lack of confidence that

a written document would change the course of treatment received [15, 23, 27–30].

2. Materials and Methods

2.1. Study Setting, Population, and Design. This study was conducted in April, 2012, within the province of Saskatchewan, a province located in Western Canada with a population just over one million people [31]. One third of the province’s population is considered rural, with the remainder divided between two urban centres.

The sample of 238 community dwelling older adults over the age 55 years represents a subgroup of the entire sample of 827 individuals obtained for a larger project, who were stratified by age, region, and sex to be representative of the population of the province. The entire sample was randomly selected from a pool of volunteers who had agreed to participate in online commercial market surveys (SaskWatch Research). Only data related to adults over age 55 years are presented in this analysis. This project received ethical approval from the University of Saskatchewan Behavioral Review Board. Participants provided consent for the data to be used in subsequent presentations and publications.

2.2. Description of Variables. The survey was comprised of structured, closed-ended items salient to planning for serious illness care. Demographic data included age; sex; personal income; education; residence (urban or rural). Respondents were asked to identify the number and type of health conditions with which they lived from a list of common illnesses, as well as to respond to the following question: “How important do you think it is to plan for medical care at the end-of-life? (not at all important, somewhat important, important, or very important).” Respondents were asked to indicate their level of knowledge about advance care planning and living wills on a three-point scale (not at all familiar; some basic understanding; fairly or very good understanding). Those who reported a written living will or advance directive were also asked to identify sources of help received with preparing this document (consultation with lawyer; consultation with lawyer and family; consultation with family; consultation with someone else; prepared by myself).

2.3. Data Analysis. Statistical analysis was completed using SPSS 19.0. Given that an age of 65 years has been recognized as the point at which many Canadians retire from paid employment, respondents were divided into two groups: those 65 and younger and those older than 65 years. Level of significance (σ) was set at 0.05. Comparisons between the groups were completed using the Kruskal-Wallis test (with multiple Mann-Whitney tests adjusted with Bonferroni corrections for post hoc analysis) and chi-square tests of proportion where appropriate. In order to determine the characteristics influencing outcome behaviors variables (discussions of unacceptable states of health; discussion of wishes for treatment, designation of a substitute decision maker; preparation of a written directive), binary logistic regression

TABLE 1: Demographic and health characteristics of the sample (by age group and overall).

| | 55–64 years (<i>N</i> = 171) % | ≥65 years (<i>n</i> = 112) % | Overall (<i>N</i> = 283) % |
|-----------------------------|---------------------------------|-------------------------------|-----------------------------|
| Sex | | | |
| Male | 45.6 | 47.3 | 47.3 |
| Female | 55.4 | 52.7 | 52.7 |
| Education | | | |
| <or completed high school | 20.1 | 14.4 | 17.9 |
| Some post-secondary | 52.1 | 55.0 | 53.2 |
| Completed postsecondary | 27.8 | 30.6 | 28.9 |
| Annual personal income | | | |
| <\$60,000 | 23.4 [†] | 42.0 [†] | 30.7 |
| \$60,000 or more | 49.7 [†] | 28.6 [†] | 41.3 |
| Refused | 26.9 | 29.5 | 21.8 |
| Residence | | | |
| Large urban | 43.3 | 41.1 | 41.4 |
| Other | 56.7 | 58.9 | 58.6 |
| Number of health conditions | | | |
| None | 27.5 [†] | 10.7 [†] | 20.8 |
| 1–3 conditions | 58.5 | 55.4 | 57.2 |
| 4 or more conditions | 14.0 [^] | 33.9 [^] | 21.9 |

[†] *P* < 0.05 using the chi-square test for proportions with a Bonferonni correction.

[^] *P* < 0.001 using the chi-square test for proportions with a Bonferonni correction.

TABLE 2: Values, knowledge, and behaviors related to planning for the end of Life.

| | 55–64 years (<i>N</i> = 171) % | ≥65 years (<i>n</i> = 112) % | Overall (<i>N</i> = 283) % |
|--|---------------------------------|-------------------------------|-----------------------------|
| Importance of planning for future medical care | | | |
| Not at all or somewhat important | 23.4 | 18.8 | 21.6 |
| Important or very important | 76.6 | 81.3 | 78.4 |
| Importance of planning for own funeral | | | |
| Not at all or somewhat important | 39.2 | 35.7 | 37.8 |
| Important or very important | 60.8 | 64.3 | 62.2 |
| Familiarity with term “living will” | | | |
| Not at all familiar | 7.0 | 6.3 | 6.7 |
| Some basic understanding | 32.7 | 30.4 | 31.8 |
| Fairly or very good understanding | 60.2 | 63.4 | 61.5 |
| Familiarity with term “advance care plan” | | | |
| Not at all familiar | 28.1 | 23.2 | 26.1 |
| Some basic understanding | 35.1 | 37.5 | 36.0 |
| Fairly or very good understanding | 36.8 | 39.3 | 37.6 |
| Discussed unacceptable states of health | 53.2 | 43.8 | 49.5 |
| Discussed wishes for treatment | 53.8 [†] | 69.6 [†] | 60.1 |
| Designated a substitute decision-maker | 34.5 [†] | 52.7 [†] | 41.7 |
| Prepared written LW or ACP | 20.5 [†] | 33.0 [†] | 25.4 |

[†] *P* < 0.05 using the chi-square test for proportions with a Bonferonni correction.

was conducted. The strength of association was measured by the odds ratio (OR) and 95% confidence interval (CI).

3. Results

Table 1 compares the demographic and health characteristics of the sample between respondents aged 55–64 years

(younger group) and those who were 65 years and older (older group). Just over half (52.7%) of the 283 respondents were females. Respondents ranged in age from 55 to 88 years. The majority (82.1%) of all respondents had education beyond completion of high school. A higher proportion of the older group reported incomes of less than \$60,000 than the younger group, while the opposite was true for incomes above \$60,000. There were no differences between the age

TABLE 3: Adjusted¹ associations between respondent characteristics and serious illness planning behaviors.

| | Discussed treatment wishes OR (95% CI) | Discussed unacceptable conditions OR (95% CI) | Designated substituted decision-maker OR (95% CI) | LW or ACP completed OR (95% CI) |
|---|--|--|--|---------------------------------------|
| Sex | | | | |
| Female (ref: male) | 2.05 [‡] (1.16–3.62) | 1.25 (0.72–2.18) | 1.21 (0.70–2.09) | 1.47 (0.77–2.80) |
| Age | | | | |
| ≥65 years (ref: <65 years) | 1.75 (0.98–3.11) | 1.23 (0.71–2.13) | 2.30 [‡] (1.32–3.99) | 1.86 (0.99–3.50) |
| Education | | | | |
| Some postsecondary education (ref: ≤high school) | 1.26 (0.60–2.65) | 1.59 (0.76–3.29) | 0.93 (0.45–1.93) | 0.98 (0.41–2.33) |
| Completed postsecondary (ref: ≤high school) | 1.64 (0.7–3.81) | 1.72 (0.75–3.92) | 0.70 (0.30–1.60) | 0.79 (0.29–2.13) |
| Annual personal income | | | | |
| ≥\$60,000 (ref: <\$60,000) | 0.62 (0.31–1.22) | 0.84 (0.43–1.61) | 1.04 (0.54–2.00) | 0.56 (0.26–1.21) |
| Unspecified (ref: <\$60,000) | 0.59 (0.29–1.26) | 0.82 (0.41–1.62) | 0.87 (0.44–1.71) | 0.86 (0.40–1.85) |
| Rural residence (ref: urban) | 0.83 (0.48–1.42) | 0.86 (0.51–1.45) | 0.65 (0.38–1.09) | 0.47 [†] (0.25–0.86) |
| Health conditions | | | | |
| 1-2 conditions (ref: 0 conditions) | 1.14 (0.53–2.49) | 0.81 (0.38–1.72) | 1.06 (0.50–2.29) | 1.05 (0.42–2.60) |
| 3 or more conditions (ref: 0 conditions) | 1.20 (0.60–2.40) | 1.30 (0.66–2.59) | 0.96 (0.47–1.89) | 0.85 (0.37–1.92) |
| Value | | | | |
| Important to plan for care (ref: not important) | 1.67 (0.87–3.19) | 1.24 (0.64–2.41) | 2.32 [†] (1.15–4.70) | 4.31* (1.42–13.07) |
| Knowledge of ACP | | | | |
| Understood term (ref: not familiar) | 3.45 [^] (1.87–6.34) | 5.62 [^] (2.90–10.92) | 2.49 [‡] (1.87–6.34) | 9.87 [^] (2.90–33.50) |

¹ Adjusted for each of the variables listed in the table.* $P < 0.10$.† $P < 0.05$.‡ $P < 0.01$.^ $P < 0.001$.

groups in location of residence. Participants residing outside of primary urban centres (populations >250,000) comprised 58.6% of the total sample. A significantly higher ($P < 0.001$) proportion of the older group reported four or more health conditions compared to the younger group, although the proportions were similar between the groups for those reporting one to three health conditions.

Table 2 compares the responses of the younger and older age groups in terms of values, knowledge, and behaviors related to planning for the end of life. The majority of respondents indicated they felt it was important or very important to plan for medical care in the event of serious illness (78.4%) and to plan for one's own funeral (62.2%). While 61.5% of respondents reported a good understanding

of the term “living will,” substantially fewer indicated they had a good understanding of the term “advance care plan.” Approximately half of all respondents had discussed states of health in which they would find it unacceptable to live with someone close to them in the past year. One-third of those aged 65 and older reported they had a written directive compared to 20.5% of adults below age 65. Respondents in the older group were significantly more likely ($P < 0.05$) to have discussed wishes for treatment, designated a substitute decision maker, and to have prepared either an advance care plan or living will.

Respondents without a written advance care plan were asked to identify reasons for not preparing this document. The majority (60.0%) indicated they had not considered this

yet, while 21.2% suggested that their families would make decisions about future health care for them and 18.2% indicated that their families together with their physician would decide. Only one respondent reported that care decisions would be made by the physician.

For the 72 respondents who had prepared a written advance care plan, the most common source of assistance to prepare the document was a lawyer (50%). A third of respondents cited families as a source of assistance, while 22.2% indicated they had completed the plan by themselves. Few (4.2%) respondents had the assistance of a health care professional in writing the directive.

Table 3 displays the adjusted association between the outcome variables (discussions about treatment wishes or unacceptable states of health; designation of a substitute decision maker; preparation of a written advance care plan) and the hypothesized predictor variables. After adjustment for all the variables listed in Table 3, women were twice as likely as men (O.R. = 2.05, 95% CI 1.16–3.62) to have discussed treatment wishes but were similar to men in terms of reporting discussion regarding unacceptable conditions, designating a substitute decision maker, or completing a written advance care plan. Those over 65 years of age were significantly more likely than those between the ages of 55 and 65 to have designated a substitute decision maker (O.R. = 2.30, 95% CI 1.32–3.99). The older group was not more likely to have completed a written advance care plan, although this association approached significance ($P = 0.06$). Education, income, and the number of self-reported health conditions were not associated with any of the four planning behaviors under consideration. Respondents from rural areas were significantly less likely (O.R. = 0.47, 95% CI 0.25–0.86) than those from urban centres to have completed a written advance care plan. Those who believed it was important to plan for care were more than twice as likely to have designated a substitute decision maker (O.R. = 2.32, 95% CI 1.15–4.70) and more than four times as likely to have completed a written advance care plan (O.R. = 4.31, 95% CI 1.42–13.07). Respondents who reported a good understanding of advance care planning had a significantly greater likelihood of engaging in all planning behaviors: discussion of treatment wishes (O.R. = 3.45, 95% CI 1.87–6.34); discussion of states of health they would find unacceptable to live with (O.R. = 5.62, 95% CI 2.92–10.92); designating a substitute decision maker (O.R. = 2.49, 95% CI 1.87–6.34); completing a written advance care plan (O.R. = 9.87, 95% CI 2.90–33.50).

4. Discussion

The findings of this study demonstrate that neither formal nor informal planning for serious illness can yet be considered widespread amongst community-dwelling adults aged 55 and older. Formal planning for serious illness, in the form of designating substitute decision makers and preparing advance care plans, was reported by fewer than half of the respondents in this study. These proportions are similar to those reported in other studies [1, 7–13]. The proportion of respondents who engaged in informal planning for serious

illness, such as conversations about treatment preferences and unacceptable health conditions, was only marginally higher, at 50% and 60%.

In examining the demographic and health variables associated with planning behaviors, women were twice as likely as men to have discussed treatment wishes with someone close to them, but just as likely as men to have discussed unacceptable states of health, to have designated a substitute decision maker, or to have prepared a written advance care plan. Similar findings were reported by Garrett et al. [21], who reported women to be more likely to consider having a conversation about end-of-life wishes, but found no sex differences with respect to preparing an advance care plan.

In the adjusted model, there were no associations between age and informal planning behaviors. Older age proved significant only for the formal planning behavior of having designated a substitute decision maker, although the association between older age and having prepared an advance care plan approached significance ($P = 0.06$). Given the formal nature of both these activities and the fact that half of the advance care plans were completed with the assistance of lawyers, it may be that older adults are more willing to consider planning for serious illness under the umbrella of estate planning than health. Interestingly, the model found no associations between the number of health conditions reported by respondents and planning behaviors. It may be that an increasing number of health conditions are an expected sequela of the aging process and insufficient in and of themselves to trigger concern that planning for serious illness is warranted.

The Transtheoretical Model [23] is increasingly used to explain variability in personal “readiness” to engage in advance care planning [20, 30]. The reason most frequently cited by respondents in this study for not preparing an advance care plan was that they “had not considered it yet.” Those individuals may have been in the “precontemplation” phase, described in the Transtheoretical Model, and were not ready to engage in formal planning behaviors. The decision to participate in planning for serious illness activities would, according to this model, mean that the “benefits” must outweigh the “costs” of the behavior perceived by the individual. The “costs” associated with the uncomfortable recognition and acceptance that one is personally vulnerable to poor health or death in the foreseeable future may have been such that respondents were not yet “ready” to engage in planning behaviors. If planning for serious illness is indeed a way to promote autonomy that is valued by older adults, it is worthwhile to further consider the factors that enhance readiness to participate in planning behaviors.

A significant proportion (21.6%) of respondents did not feel planning for future medical care to be important. Those who did not consider planning to be important were significantly less likely to have designated a substitute decision maker or have completed a written advance plan. While governments and health care providers continue to promulgate the benefits of planning for serious illness, it is important to bear in mind that a significant proportion of our patients may not share this value. Nurses who seek to educate patients about strategies to plan for future medical

care must first take the time to appraise whether, in fact, a given individual believes these activities to be of value. Understanding the experiences that shape the individual's perspective on advance care planning is critical to a truly "patient-centred" approach.

Knowledge about advance care planning was consistently and independently associated with all types of planning for serious illness behaviors (discussions about treatment wishes or unacceptable states of health; designation of a substitute decision maker; preparation of a written advance care plan). The fact that respondents from rural areas, however, were only half as likely as those from urban areas to have an advance care plan suggests that access to information about planning for serious illness may, in fact, be a key driver for planning behavior. While the survey did not evaluate the access respondents had to education about advance care planning, access to health services is often limited in rural settings (CIHI). It is worthwhile to bear in mind, however, that the association between knowledge and behavior does not demonstrate causality, whereby more education about advance care planning leads directly to greater participation in planning. Individuals who were already receptive to the importance of planning for serious illness may have availed themselves of opportunities to educate themselves about this process. Nurses may play a significant role in identifying "teachable moments" and providing support and education to those who demonstrate an interest and willingness to learn more about ways to best plan for future serious illness. Tailoring interventions to the individual's level of readiness is referred to as "stage-matching" within the Transtheoretical Model [32].

5. Limitations

While this survey was representative of the population of the province in terms of sex and region, the sample did not include the entire population of the province. Stratification by socioeconomic status or additional variables was not possible, although level of education may reflect socioeconomic status to some extent. Random selection occurred from the pool of those individuals who had agreed to participate in online surveys conducted by SaskWatch Research, and thus selection bias may have been present. Verification that ACP or LW documents were completed was not possible.

6. Nursing Implications

Supporting the autonomy of older adults is a key concern of nursing practice. Education of the patients with respect to the process of advance care planning has been recognized as a public health issue in which nurses may make a significant contribution. As advocates for supporting the autonomy of older adults, however, nurses who engage in practice related to advance care planning must keep in mind that, for almost one quarter of respondents in this study, planning for serious illness was not considered important. That some individuals do not hold planning as a value is an important consideration when planning nursing interventions designed

to educate and foster participation in advance care planning, highlighting the need to match interventions to levels of readiness.

Conflict of Interests

The author has no conflict of interests to declare.

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Research Article

Models for Designing Long-Term Care Service Plans and Care Programs for Older People

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The establishment of a system for providing appropriate long-term care services for older people is a national issue in Japan, and it will likely become a worldwide issue in the years to come. Under Japanese Long-term Care Insurance System, long-term care is provided based on long-term care programs, which were designed by care providers on the basis of long-term care service plans, which were designed by care managers. However, defined methodology for designing long-term care service plans and care programs has not been established yet. In this paper, we propose models for designing long-term care service plans and care programs for older people, both by incorporating the technical issues from previous studies and by redesigning the total methodology according to these studies. Our implementation model consists of “Function,” “Knowledge Structure,” and “Action Flow.” In addition, we developed the concrete knowledgebases based on the Knowledge Structure by visualizing, summarizing, and structuring the inherent knowledge of healthcare/welfare professionals. As the results of the workshop and retrospective verification, the adequacy of the models was suggested, while some further issues were pointed. Our models, knowledgebases, and application make it possible to ensure the quality of long-term care for older people.

1. Introduction

Japan is known as a “super-aging society [1],” because of long life expectancy and a low birth rate [2]. The population-aging rate (population over 65 years old/total population) in Japan was 23.1% in 2011, which was the highest worldwide [3]. The establishment of a system for providing appropriate long-term care services for older people is a national issue in Japan, and it will likely become a worldwide issue in the years to come [4–6]. In response to this increasing social need for appropriate long-term care services, the Long-term Care Insurance System was instituted in April 2000 in Japan [1]. More than 16.5% of the older people over 65 years of age were using this insurance system in 2008 [7], accounting for about 4,673,000 among the total population of older people (28,317,000).

There are two management cycles under this insurance system (Figure 1): one for long-term care service plans, run by care managers, and one for care programs, run by care providers. Long-term care services are based on long-term care service plans, which consist of goals, care services to

be provided, estimated care contents, schedules for care services, and so on. Care managers design the long-term care service plans by assessing the condition of an older person and can consult other healthcare professionals concerned—doctors, nurses, and social workers—if needed. Then, each care provider designs a concrete care program based on this long-term care service plan and provides care services according to this care program. Care programs consist of concrete care contents, detailed schedules for care, and so on.

“Excessive care,” “long-term care prevention,” and “dementia care” are mentioned as the three main problems by Muraoka et al. [8]. In this study, we focus on the physical care and exclude the mental aspect of care like dementia care and so on. While there are some studies on “long-term care prevention [9–11],” we focus on minimizing or preventing “excessive care.” Excessive care refers to provide higher level of care than the person’s actual needs, by corresponding to the person’s “demands” or by working for care providers. It serves the care provider’s interest and makes the older person comfortable in the short-term. However, it works to

the detriment of the older person by reducing the disuse syndrome in the long-term.

In designing long-term care service plans, care managers utilize assessment tools, which are represented by interRAI HC (Resident Assessment Instruments Home Care) [12], and so forth, to analyze problems of the person. However, it is still difficult to design long-term care service plans and care programs that are based on the output of these assessment tools, because the solutions are not associated with the problems in these assessment tools. In the current situation, long-term care service plans are usually designed without determining concrete contents of care, and care programs are usually not designed based on the specific condition of each older person. As a result, the quality of long-term care service plans, long-term care programs, and therefore the quality of long-term care for older people has been dependent upon the particular experience or attitude of a care manager or care provider. Thus, it is necessary to establish appropriate processes for designing long-term care service plans and care programs according to the specific condition of each older person.

With respect to the background provided above, Kato et al. [13] proposed a process model for determining elderly care according to ADL (activities of daily living). This model would help care managers determine the concrete contents of care suited to an elderly person's ability to perform each ADL. In addition, Kato et al. [14] developed the necessary knowledge contents for ADL items that would be used in the process model for determining elderly care. Using this model and the knowledge contents, we can more precisely determine concrete contents of care suited to an elderly person's ability to perform each ADL.

However, these individual studies have not managed to establish a complete methodology for designing long-term care service plans and care programs, for two reasons. First, these studies had a limited scope and did not examine the full range of issues in elderly care. Second, they had a few technical issues: the model could not be adapted to suit individual environmental needs; it was difficult to determine which care services should be included according to the output of the model, because care services were not associated with individual care options, and so on.

In this study, we propose a logical model and implementation model for designing a long-term care service plan for older people, both by incorporating the technical issues from previous studies and by redesigning the total methodology according to these studies [13, 14]. We interpreted the design of a long-term care service plan and care program as the design of practicable measures that can satisfy the needs of an older person, which can be considered as a "needs-seeds problem"; accordingly, we have designed an appropriate model. We resolved the above two problems noted in the previous studies and endeavored to help care managers and care providers visualize and develop more structured thinking processes. This study is limited to long-term care in terms of ADL items, because we consider ADL to be one of the most fundamental parts of a person's life.

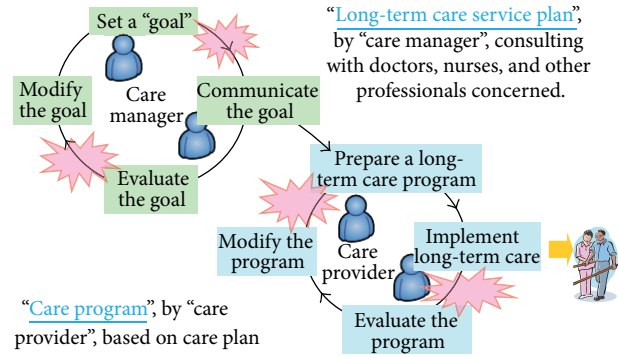


FIGURE 1: Management system under the Long-term Care Insurance System.

2. Materials and Methods

2.1. Designing the Models

2.1.1. Core Concept. We interpreted the processes of designing a long-term care service plan and care program as a process of designing practicable measures to satisfy the care needs of an older person. Long-term care is required when an older person wants to realize a specific way of daily living, depending on the person's current ability and the conditions of their home/care facility. That is, when an older person wants to realize a specific way of daily living, he or she requires various physical and mental abilities, and acquiring such abilities depends on the conditions of his or her home/care facility. If the older person has sufficient ability, he or she might be able to realize the way of daily living by him or herself. However, if he or she does not have sufficient ability, he or she would not be able to realize this way of daily living independently and thus would require assistance. Some care services are planned to provide such assistance. From this fundamental concept, we propose the core concept for designing a long-term care service plan and care program, as shown in Figure 2.

This process of designing a long-term service plan and care program involves different duties for care managers and care providers. These duties share many elements and can be categorized as the following six “functions.” Care managers are responsible for Functions 1–6, while care providers perform Functions 1–5 using the guidelines of the long-term care service plan.

- Function 1: Assess the person's ability
- Function 2: Assess home/care facility condition
- Function 3: Assume a hypothetical way of daily living
- Function 4: Identify care needs
- Function 5: Design care program
- Function 6: Design long-term care service plan.

2.1.2. Designing the Logical Model. The first step of this study was limiting the scope of older people's ADLs to focus on six items: moving, dressing, eating, grooming, urinating, and bathing. We did this according to previous literature [15–17].

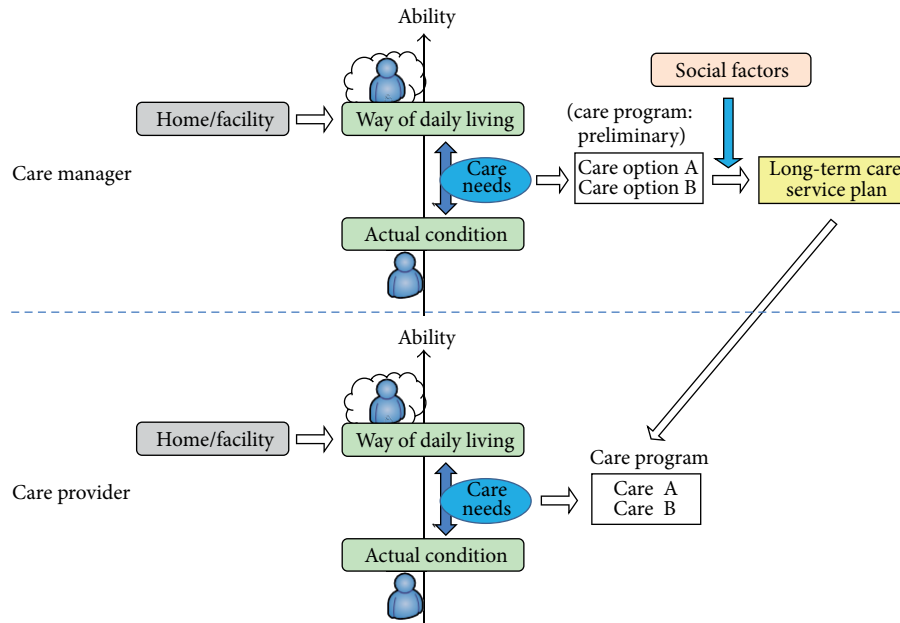


FIGURE 2: Core concept.

In general, there are multiple ways to perform each ADL. To express the variety of ways, an ADL needs to be broken down into individual “element actions.” At that point, each ADL can be expressed as a “realization pattern,” which is a combination of multiple element actions. To evaluate whether the older person can achieve each element action independently, “ability elements” are introduced as indicators to assess the person’s condition. The actual condition of the person can be quantitatively expressed as a score for each ability element, which is referred to as “actual ability.” The ability required for the person to perform an element action is referred to as the “required ability for element action.” Required ability also depends on some conditions of the residential area where the person is living, which are referred to as “home/facility conditions.” Then, for each ability element, a gap is identified by comparing actual ability with required ability for each element action; the gaps between actual and required ability represent the needs to be met by long-term care.

Generally, there are multiple care options to satisfy these identified care needs. The required ability for a person to perform a certain element action called for by a given care option is referred to as “required ability for care.” Each care option is evaluated on whether it can satisfy the person’s care needs, by comparing the actual ability with the required ability for care. In addition, multiple care services might be able to provide the required care. The long-term care service plan should be designed by considering social factors such as financial problems or family issues. Thus, according to the above consideration, we designed the logical model.

2.1.3. Designing the Implementation Model. As described below, we suggest that each function in the logical model should consist of multiple information conversions, and

factors to be considered, like element action, ability element, care, and so forth, would be deployed into a considerable number. Thus, we needed to design an implementation model, by further specifying the functions, structuring the information flow, and developing the knowledgebases according to structured knowledge from experts. In this study, we created three concrete components for this implementation model: “Function,” “Knowledge Structure,” and “Action Flow.”

2.1.4. Developing the Knowledgebases and Application. We developed concrete knowledgebases, based on the Knowledge Structure, in collaboration with care managers, doctors, nurses, and social workers in the Ohme area. In the development process, we applied the knowledge contents for twelve actual cases that were being handled by concerned professionals to ensure that the knowledgebases were accurate.

In addition, we developed a specific computer application using Microsoft Excel and Visual Basic for Applications (VBA), known as the “prototype system,” in order to carry out the methodology specified in the implementation model.

2.2. Methods for Verification of the Model. In an attempt to perform initial validation of the proposed model, one of the authors (Kato) held a workshop together with five care managers (two newly recruited, two experienced, and one advising) to design care programs for some older people at the one of care facilities in Tokyo.

2.2.1. Preparing the Cases. In this workshop, Kato and the care managers developed care programs for two actual cases. The actual cases were in the charge of the advising care manager, and neither the other care managers nor Kato had prior information about these cases. One was the case of higher

care-need level (level 5), and another was the case of lower care-need level (level 1).

In this workshop, we limited the ADL item of urinating. care for eating, urinating, and bathing are known as the “three major care” in Japan, and the forms of care for urinating changes a lot based on the person’s condition in these three, so we considered that focusing on urinating was appropriate as the first step.

2.2.2. Grouping. Kato and the four care managers were divided into three groups (A, B, and C). A newly recruited care manager and an experienced care manager were included in both Groups A and B, aiming to reduce the variation between groups. Kato was the only member of Group C.

Group A did not use the model and carried out all the steps manually, while Group B used a format sheet on Excel, that reflected the implementation model (Function, Knowledge Structure, and Action Flow), but without knowledgebases. It means that the Group B designed care programs, by developing required knowledgebases by themselves according to the format sheet. This group was received the instruction of the use of the format sheet before starting the workshop. Group C used the prototype system containing the knowledgebases. It means that the output of Group C would not depend on the specific professional ability of the group member, but would depend on the prototype system.

2.2.3. Designing Care Programs. Every participant independently designed care programs for two cases, after receiving explanations for each case from the advising care manager together. The amounts of time required were approximately 10 to 20 minutes for each case per participant.

2.2.4. Preparing the Reference Programs. It was difficult to evaluate the output of each group by directly comparing them, because both the expression form and granularity of the description were quite different. We prepared the reference program by modifying the output of the prototype system based on the opinion of the advising care manager, to make it possible to compare the output of each group.

2.2.5. Evaluating the Output of Each Group. As the evaluation indicators of care program, we adopted three indicators: completeness, definiteness, and accuracy [13, 14].

These factors were assessed through discussions among all the participants of the workshop by comparing the outputs of the three groups with a reference program.

2.3. Methods for Verification of the Knowledgebases and Application. We conducted a retrospective verification of the knowledgebases and application with 7 healthcare/welfare professionals by using the prototype system in Tokyo.

2.3.1. Selecting Cases. We applied the prototype system to total 50 actual cases who were in the charge of seven experienced (each having more than five years) healthcare/welfare

professionals (two nurses: N1 and N3; two social workers: S4 and S5; and three care managers: M1, M3, and M4).

We asked the participating healthcare/welfare professionals to select various cases, that is, various levels of care-needs, age, causative diseases, and so on, for application to confirm the validity of our proposal.

2.3.2. Evaluating the Knowledgebases and Application. As the evaluation indicators of care program, we adopted “effectiveness to provide excessive care” in addition to the previous three indicators as listed in Section 2.2 (completeness, definiteness, and accuracy).

These 4 indicators were used as a basis to create the following 4 questionnaires, and we asked the participating healthcare/welfare professionals to evaluate the following four points, for five ADL items: dressing, eating, grooming, urinating, and bathing. Eventually, we evaluated these indicators for a total of 250 ADL items.

R1: Does the judgment made on each element action and care option in the output agree with the real life situation of the case, as understood by the professionals in charge of that case? (Characteristic 3: accuracy)

R2: Are there ambiguous or difficult to understand expressions in the output of the prototype system? (Characteristic 2: clarity)

R3-1: Did the real life situations follow the system-derived plan? (Characteristic 1: completeness)

R3-2: Are there any element actions or care options lacking from the output? (Characteristic 1: completeness)

R4: Was there a more appropriate realization pattern from a longevity perspective? (Characteristic 4: effectiveness)

3. Results and Discussion

3.1. Results: Logical Model. The designed logical model is shown in Figure 3. The logical model is a methodology for designing a long-term care service plan and accompanying care programs, by showing all the elements that need to be considered in this process as well as the relationships between them. The six functions in the logical model are described as follows.

3.1.1. Function 1: Assess the Person’s Ability. We evaluate the actual condition of an older person. An “ability element” is a scale used to assess a person’s condition, such as the “ability to see,” and “ability to keep standing position.” The actual condition of a patient can be quantitatively expressed as a score for each ability element, which is referred to as “actual ability.” If the person used any wearable supporting devices, we must assess the ability of the person separately for instances where devices were worn and for those where they were not worn.

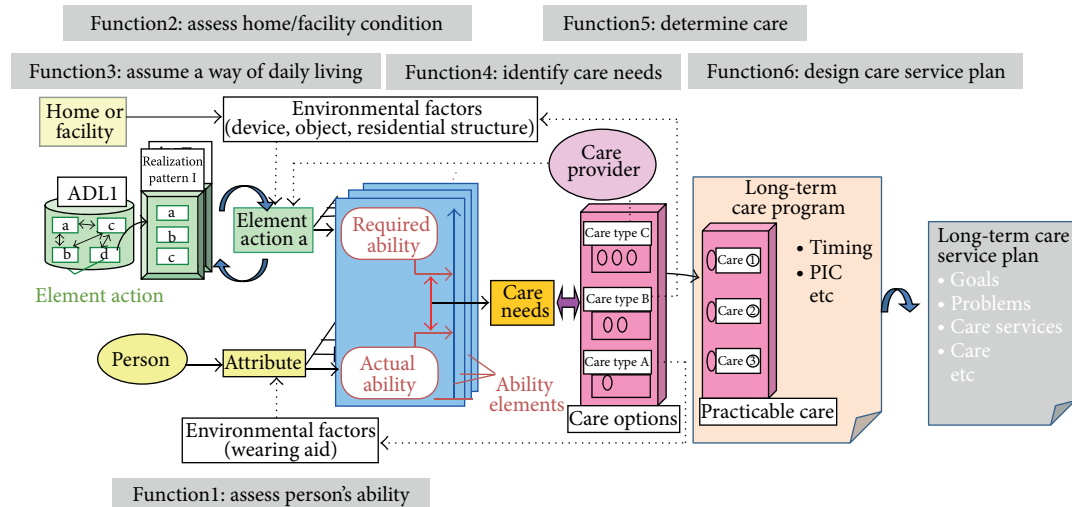


FIGURE 3: Logical model.

3.1.2. Function 2: Assess Home/Care Facility Condition. We assess the condition of the person's home/care facility, because it is necessary to consider the functional design and residential structure of home/care facility where the person is living, as well as the available human and physical resources, among other aspects.

3.1.3. Function 3: Assume a Hypothetical Way of Daily Living. We assume an example way of daily living, which that person might want to realize. We do this by assuming how the person currently performs each ADL. In general, there are multiple ways to perform each ADL. To express the variety of ways in which each ADL item can be achieved, each ADL must be divided into more basic "element actions." Subsequently, each ADL is expressed as a "realization pattern," which is a combination of multiple element actions based on the condition of that person's home/care facility.

It is not always the best way to determine simply the way of daily living which the older person or families "want," because there are comprehension gradients between care managers and the older person/families. We need to assume a way of daily living here, based on the results of Function 1 and 2, by considering the hopes of the person/families.

3.1.4. Function 4: Identify Care Needs. Here, we identify an elderly person's needs for long-term care. The ability required for a patient to perform an ADL for the way of daily living that person is seeking is referred to as "required ability for element action." For each element action in the realization pattern, ability gaps are identified by comparing the actual ability with the required ability for element action. These ability gaps represent that person's care needs.

3.1.5. Function 5: Design Care Program (Preliminary). Here, we determine a feasible method for satisfying the identified care needs. These methods are classified into two types. One method is "decreasing the required ability for action," which can be achieved by improving the environmental conditions,

using supporting devices, and providing assistance. The other method is "improving actual ability," which can be achieved by rehabilitation training or by the use of wearable supportive devices (e.g., eyeglasses or acoustic aids).

The practicable measures for each older person are selected from the multiple long-term care options capable of filling the ability gaps that were identified for each element action, by comparing the actual ability with the required ability for care.

Then, we designed a care program by determining the frequency and timeline for the implementation of long-term care and the person in charge (family or service provider), by considering the hopes of the person/families.

3.1.6. Function 6: Design Long-Term Care Service Plan. Finally, we design a long-term care service plan based on the preliminary care program, by considering social factors like financial problems or family issues and hopes of the person/families.

3.2. Results: Implementation Model. For the Implementation Model, Table 1 shows the "Function" component; Figure 4 shows the "Knowledge Structure" component; and Figure 5 shows the "Action Flow" component. The Function component computes the various information conversions that can be used to find a final solution; Knowledge Structure indicates the structure of knowledge used to implement the Function; finally, Action Flow represents the procedure and flow of information during implementation of the model's methodology.

As shown in Figure 4, the knowledge contents based on this Knowledge Structure were converted into four knowledgebases: "Ability Assessment Sheet," "Home/Facility Assessment Sheet," "Table of Required Ability for Element Action," and "Table of Required Ability for Care."

For example, Figure 6 shows the parts of Function 3–1, by using the table of required ability for action. In this example is expressing the parts of results of 3–1 for "dressing."

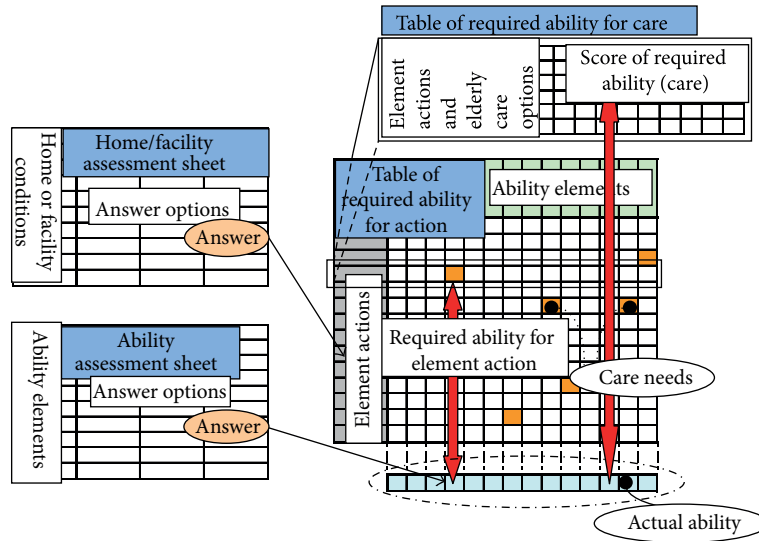


FIGURE 4: Knowledge Structure.

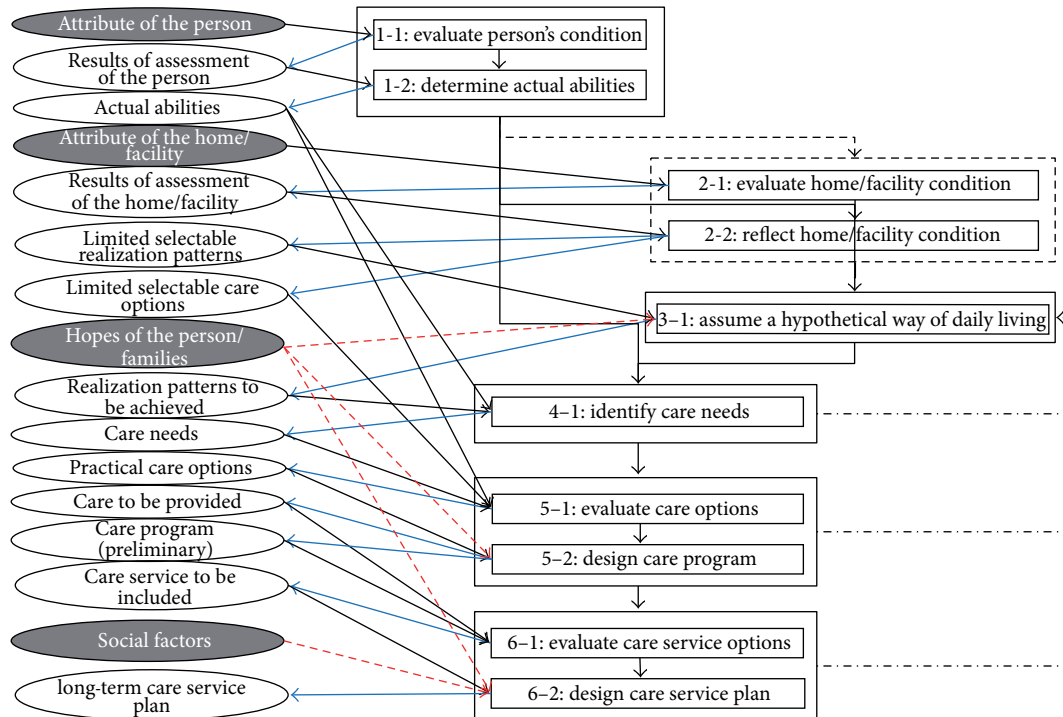


FIGURE 5: Action Flow.

| Element actions | Ability to move one's hand to bosom | Ability to move one's hand to back | Ability to move weighing object | Skill with the hands | ... |
|------------------------------|-------------------------------------|------------------------------------|---------------------------------|----------------------|-----|
| Getting upper clothes on | 5 | 3 | 3 | 2 | ... |
| Doing up buttons, zipping up | 5 | | Care needs | 4 | ... |
| Actual ability | 5 | 3 | 3 | 3 | ... |

FIGURE 6: Example of Function 3-1 (partial).

In this realization pattern, element actions like “getting upper clothes on,” “doing up buttons, zipping up,” and so forth and ability elements like “ability to move one’s hand to bosom,” “ability to move one’s hand to back,” “ability to move weighing object,” “skill with the hand,” and so forth are included. Care need is identified for the element action “doing up buttons, zipping up” on ability element “skill with hand,” because the required ability for this element action on this ability element is set as 4, which is higher than the actual ability assessed as 3.

TABLE 1: Function.

| Name | Input | Activity | Output | Required knowledgebase |
|--|---|---|---|--|
| 1: assess the person's ability | 1-1: evaluate person's condition | Evaluate person's condition | Results of assessment of the person | Ability assessment sheet |
| | 1-2: determine actual abilities | Determine actual ability of the person on the basis of the results of 1-1 | Actual abilities | (Logic for determining actual abilities: included in ability assessment sheet) |
| 2: assess home/facility condition | 2-1: evaluate home/facility condition | Evaluate environmental condition of the home/facility, where the person will live | Results of assessment of the home/facility | Home/facility assessment sheet |
| | 2-2: reflect home/facility condition | Limit selectable realization pattern and care option on the basis of the results of 2-1 | (i) Limited selectable realization patterns (ii) Limited selectable care options | (Table of limitation to realization pattern and care option: included in the home/facility assessment sheet) |
| 3: assume a hypothetical way of daily living | 3-1: create a hypothetical mode of life | Set (multiple) realization patterns for the person on the basis of the results of 2-2, considering the hopes of the person/families | Realization patterns to be achieved | (List of Realization Pattern: included in the table of required ability for element action) |
| 4: identify care needs | 4-1: identify care needs | (i) Realization patterns to be achieved (ii) Actual abilities | Care needs | Table of required ability for element action |
| 5: design care program (preliminary) | 5-1: evaluate care options | (i) Care needs (ii) Limited selectable care options (iii) Actual abilities | Practicable care options | Table of required ability for care |
| | 5-2: design care program | (i) practicable care options (ii) <i>hopes of the person/families</i> | (i) Care to be provided (ii) Care program | — |
| 6: design long-term care service plan | 6-1: evaluate care service options | Determine care services to implement elderly care selected in 5-2 | Care services to be included | Table of care service option |
| | 6-2: design care service plan | (i) care services to be included (ii) <i>hopes of the person/families</i> (iii) <i>social factors</i> | Design a long-term care service plan on the basis of the results of 6-1, considering the hopes of the person/families Long-term care program | (Design item (PIC, Timeline, etc.)) |

3.3. Results: Knowledgebases and Application of the Model. We developed the knowledgebases within the scope of the implementation model. For example, the Table of Required Ability for Element Actions contains 125 element actions and an organized Required Ability list, which was created using 32 Ability Elements.

In addition, we developed a specific application using Excel and VBA. The methodology specified by the implementation model can be carried out using this application, referred to as the “prototype system.” The prototype system carries out Functions 2~5 after the user has performed Function 1. Therefore, the user can practice functions 5~2 to 6~2, with supporting information from the prototype system (functions are shown in Table 1).

3.4. Results: Verification of the Model. The results of Section 2.2.5 are summarized in Table 2. In Table 2, three evaluation indicators (completeness, definiteness, and accuracy) are arranged and are divided into subindicators in vertical row, and care managers are arranged for each case in the horizontal row. Two realization patterns were assumed for the second case. In Table 2, numbers of differences between each output from the reference program are described in each cell. The smaller these numbers are, the better the quality of each output is.

For example, for “shortage of cares” in each output for the first case, there were 8 shortages of cares in the output of A1, 4 in that of A2, 4 in that of B1, 1 in that of B2, 2 in that of C (by knowledgebases before modification), and 0 in that of C (by modified knowledgebases). For this subindicator, we can evaluate that the quality of each output is in the following order: $C^* > B2 > C > B1 = A2 > A1$.

According to the three evaluation indicators, we found that the overall outputs of Group C were the best, followed by those of Group B and then Group A. The outputs of Group B, which used the format representing the Function, Knowledge Structure, and Action Flow, were found to be better than those of Group A, which did not use the logical model at all. Further, the outputs of Group C, which used the entire implementation system, were better than the outputs of Group B.

When examining some parts of the outputs, however, the ranking order mentioned above (Group C, Group B, and then Group A) was not necessarily valid. A comparison between Groups A and B revealed that some of the outputs of Group A were better than the corresponding outputs of Group B. The overall outputs of Group C were of a higher quality because Group C used the knowledgebase built using the implementation system. Group C, however, failed to present some outputs which Groups A and B were able to produce.

When we compared the outputs of the newly recruited care manager (expressed as “fresh” in Table 2) and the experienced care manager from the same group, we found that some outputs of the newly recruited care manager were better than the corresponding outputs of the experienced care manager.

3.5. Results: Verification of the Knowledgebases and Application. The results of Section 2.3.2 are shown below.

(R1-accuracy): Does the Judgment Made about Each Element Action and Care Option in the Output Agree with the Real Life Situation of the Case, as Understood by the Professionals in Charge of That Case? There were a total of 22 misjudgments of element actions or care options by the prototype system when applied to a total of 50 cases and 250 ADL items. Each ADL item was expressed as realization patterns made by approximately 5–15 element actions. The breakdown of mistakes found in the output judgments is as follows:

M1 (care manager): 13 (within five cases)

N1 (nurse): 8 (within eight cases)

M3 (care manager): 1 (within six cases).

We consider that the rate of mistakes in the output of the prototype system is sufficiently low, and it is possible to reduce the rate further by improving the knowledgebases continuously in the future. We can say that the knowledgebases and the application have enough accuracy from these results.

(R2-Definiteness): Are There Ambiguous or Difficult to Understand Expressions in the Output of the Prototype System? There are no ambiguous and unclear expressions pointed in the output when applied to a total of 50 cases. We can say that the knowledgebases and the application have enough definiteness from this result.

(R3-Completeness): Did the Real Life Situations Follow the System-Derived Plan? (R3-1), Are There Any Element Actions or Care Options Lacking from the Output? (R3-2) Real-life situations were found among the possible realization patterns for 249 of the total 250 ADL items without shortage of the realization patterns. While some actions for the preparation/management of environmental factors were indicated as absent in the realization pattern, these factors were judged to be unnecessary as the standard output at this time through discussion among participants of the workshop.

We can say that the knowledgebases and the application have enough completeness of realization patterns, element actions, and care options, while some further issues were suggested.

(R4-Effectiveness to Prevent Excessive Care): Was There a More Appropriate Realization Pattern from a Longevity Perspective? For 125 of the 250 ADL items, participating professionals found a realization pattern considered to be more appropriate than the current one utilized by the case, from the perspective to prevent excessive care. For example, there are some cases, where older people were eating with total assistance by care provider, in spite of the fact that they could eat with only partial assistance.

It is usually difficult for care manager or care provider to lower the level of assistance without some kind of evidence. We can say that our application with the knowledgebase has the potential to be used as such evidence and will contribute to minimize excessive care.

TABLE 2: Results of the verification.

| Evaluations | Case I (Normal) | | | | | | Case, care manager | | | | | | Case II (Portable Toilet) | | | | | |
|-----------------------------|---|--------------------|---------------------|---------------|--------------------|--------------------|--------------------|--------------------|---------------------|---------------|--------------------|--------------------|---------------------------|--------------------|---------------------|---------------|--------------------|--------------------|
| | A1 (fresh) | A (experienced) | A2 (experienced) | B1 (fresh) | B (experienced) | C (experienced) | A1 (fresh) | A (experienced) | A2 (experienced) | B1 (fresh) | B (experienced) | C (experienced) | A1 (fresh) | A (experienced) | A2 (experienced) | B1 (fresh) | B (experienced) | C (experienced) |
| Completeness | | | | | | | | | | | | | | | | | | |
| Shortage of element actions | 9 | 5 | 4 | 4 | 4 | 1 (0)* | — | — | — | 4 | 5 | 1 (0)* | 7 | 6 | 6 | 3 | 3 | 1 (0)* |
| Shortage of cares | 8 | 4 | 4 | 4 | 1 | 2 (0)* | — | — | — | 4 | 3 | 2 (0)* | 8 | 8 | 8 | 4 | 2 | 2 (0)* |
| Definiteness | 1 | 2 | 0 | 0 | 0 | 0 | — | — | — | 0 | 0 | 0 | 1 | 1 | 1 | 0 | 0 | 0 |
| Accuracy | Misjudgment for element actions (misjudged as NG) | | | | | | | | | | | | | | | | | |
| | 2 | 2 | 2 | 2 | 0 | 2 (0)* | | | | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| | Misjudgment for element actions (misjudged as OK) | | | | | | | | | | | | | | | | | |
| | 1 | 2 | 1 | 1 | 0 | 0 | — | — | — | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| | 2 | 2 | 2 | 2 | 0 | 0 | | | | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| | 3 | 6 | 3 | 3 | 0 | 1 (0)* | | | | 0 | 0 | 2 (0)* | 0 | 0 | 0 | 0 | 0 | 2 (0)* |

* Number by Knowledgebases before modification (number by modified Knowledgebases).

3.6. Discussion

3.6.1. Initial Validation of the Model. We consider the logical model to be valid, because of the overall results of the workshop—which indicated that Group C had the best procedure, followed by Group B and then Group A—as well as the results of the application to actual cases.

In the workshop, the care managers of Group B were able to effectively utilize their experience and expertise because they used the format reflecting the implementation model. As a result, Group B was able to generate higher quality outputs than Group A. Group A performed better than Group B on several areas; however, we concluded that the experience and expertise of the therapists from Group A was superior in those areas to that of the therapists from Group B. The outputs of Group C were of a higher quality because its sole member used the knowledgebases that we designed in the initial phase of our study. However, Group C failed to present some outputs that Groups A and B were able to produce. We believe this is because the knowledgebases used in this workshop was developed with only a few professionals, and there is room to further improve the scope of the knowledgebases.

The workshop was held with a minimum size of cases and care managers. While we consider that the results were enough as the initial validation of the model, we will need more tests in the future through expanded size of cases and care managers.

3.6.2. Validation of the Knowledgebases and Application. In the application to actual cases, the adequacy of the knowledgebases and application was confirmed on four evaluation indicators: completeness, definiteness, accuracy, and effectiveness to prevent excessive care. According to the results in Section 3.5, it was suggested that our knowledgebases and application would have the potential to be supporting evidence for the appropriate level of care and would contribute to minimize or prevent excessive care.

It was also suggested that the quality of the knowledgebases needed to be improved continuously for future studies. In this study, we have developed the knowledgebases with a small number of care managers in an area in Japan. Therefore it is possible that the scope of the knowledge is dominated by the characteristics of the region. We will need more test widely in the future in the various areas in Japan.

3.6.3. Significance of the Model. We believe that our model will be able to meet the social needs of Japan and perhaps might eventually meet those needs across the world, as there is currently no existing standardized methodology for designing long-term care service plans. This is due in part to the characteristics and structure of the essential problem: the “needs-seeds” problem. We interpreted the designing of a long-term care service plan and care program as designing practicable measures to satisfy the care needs of an older person; in our model, we did this by converting a way of daily living into component elements and the required ability for those elements, and therefore relating the care options to the ability gaps.

We developed concrete knowledgebases by using the Knowledge Structure that we designed. However, the case study results suggested that the Knowledge Structure itself was adequate. In addition, it is more important that we develop an adequate body of knowledge (BOK) in this area and make it accessible and improvable, as those are essential factors in the establishment of the methodology as a sociotechnical system [18, 19].

Our model is designed specifically for long-term care. By generalizing accordingly, however, this model can serve as the basis for a common model that can be used to design practicable measures to satisfy needs expressed as gaps between actual conditions and assumed conditions. We plan to attempt to apply this model to various issues in elderly care and then improve it to the point that it could perhaps handle each individual issue.

In addition, our model includes the perspective of “designing tool for ways of daily living,” and it can be available for various professionals and people other than care managers and care providers. While we consider that any special skills are not strongly required for the use of our model, professionals like nurses, social workers, therapist, and so forth, who have a skill for evaluation of daily living, will benefit as they can use our model to be more effective and efficient. For people without such a skill, our model is expected to work as an educational tool for evaluation of daily living.

3.6.4. Future Issues. We need further consideration on the acknowledgment-of-ability elements. Further study on these abilities (i.e., individualized functions) is also under way in this specialized field. In the future, we will endeavor to develop proper indicators (ability elements) and identify the relationships between acknowledgement-of-ability elements and element actions. Once this issue is resolved, we believe that it will be possible to precisely estimate the required time for providing care to a target client, as well as to conduct a benchmark test for the current Long-Term Care Insurance System.

In this study, we developed knowledgebases focusing on ADL and outlined a set of functions (1–5) that were covered by these knowledgebases. However, we need to extend the scope of these knowledgebases to include elements other than ADL and more fully cover Function 6 in the future.

In addition, we developed the knowledgebases by structuring the technical knowledge obtained from a specific group of healthcare/welfare professionals. Therefore, the knowledgebases could partially depend on their specific knowledge. In addition, the knowledge bases could depend upon cultural and social values. In the future, we will need to consider these issues in other groups of healthcare/welfare professionals and make further verifications to develop more standardized knowledgebases.

3.6.5. Integration of the Proposed Model into PCAPS-IMT. To ensure quality healthcare, Iizuka et al. [20] proposed a system known as the PCAPS-IMT (patient condition adaptive path system). The distinguishing feature of this system is that

it adapts to the individual patient's particular conditions. PCAPS-IMT consists of two tools. The clinical process chart encompasses the overall flow of clinical judgments and treatments that can be considered for a type of disease, consisting of clinical unit processes, and the unit sheet specifies a set of treatments, tests, observations, and other clinical treatments to be conducted in a unit clinical process to manage the total activities by the clinical team.

To obtain a satisfactory performance using this system, it is necessary to correctly understand the patient's specific conditions. Therefore, we consider that it is possible to integrate the process model for determining elderly care into the PCAPS-IMT as an evaluation model for patient scenarios. In particular, we consider it to be applicable during periods of convalescence, where the degree of dependence upon nursing is critical. Accordingly, we will consider applying our model in such situations.

4. Conclusions

In this study, we have developed a model that can be used to design appropriate long-term care service plans and accompanying care programs. Furthermore, through the implementation model we also established knowledgebases for long-term elderly care and a prototype system using Excel and VBA. By using the proposed model, it is possible to efficiently and effectively design a long-term care service plan and care program suited to the way of daily living, which an older person wants to realize.

To promote sustainable growth in society, it is essential to meet the social needs associated with the long-term care of the elderly. This study is expected to contribute considerably in the efforts to ensure long-term care for the elderly and improvement of the quality of such care.

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Research Article

How Older Female Spouses Cope with Partners' Coronary Artery Bypass Graft Surgery

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This research sought to better understand how older female spouses cope with a partner's coronary artery bypass graft surgery and to explore coping's relationships with life-change stress, cognitive appraisal, resilience, social support, and aspects of spouse's surgery. A sample of 96 women, aged from 55 to 81 years, completed surveys after their partner's surgery. Folkman and Lazarus' ways of coping (WCQ) scales yielded two factors in this sample—reactive coping and adaptive coping. Reactive coping, including more emotion-focused ways of coping from the WCQ, was associated only with more time spent anticipating spouses' surgeries. Women described the greatest use of ways of coping labeled adaptive, which in turn had significant relationships with greater resilience, social support, and positive appraisal of the surgical experience. Stepwise multiple regression found greater resilience, more frequent religious participation, and fewer children to be distinct predictors of adaptive coping. Nursing staff are encouraged to accept and normalize reactive coping, while facilitating adaptive coping with surgical stresses.

1. Introduction

The leading cause of noncommunicable death (NCD) worldwide in 2008 was cardiovascular disease, accounting for 17 million, or 48%, of all NCD deaths [1]. Heart disease may lead to patients' physical and emotional distress, job loss, disability, and reduced quality of life [2–4]. While much empirical research suggests that coronary artery bypass graft (CABG) surgery is stressful for the patient [5], the patient's spouse may be under more stress than the patient [6, 7]. The spouse may demonstrate poorer psychological adjustment and higher levels of anxiety and depression than the patient [6], both immediately and following acute cardiac events, such as acute myocardial infarction (AMI), heart failure [8], CABG surgery [2], as well as during the first 3 months after hospital discharge [9, 10]. During and after acute cardiac interventions, spouses may well be “forgotten” in an environment devoted to the patient [11–13]. Spouses may also be more immediately concerned about the changing marital roles, as the burden of care giving and other responsibilities falls on their shoulders [6, 7].

While the impact of partners' CABG surgery upon spouses is well documented in general, there is a dearth of research concerning how the older female spouse copes with her partner's acute surgical event. Artinian's research [11, 12, 14], along with Dracup et al.'s work [8], has addressed multiple factors that may affect the spouse's coping with a partner's cardiac event, such as cognitive appraisal of the event's impact, personal resilience, amount of social support, and recent family life-change stress. Research that furthers understanding of how older female spouses cope with a partner's CABG surgery may contribute to spouses' welfare, as well as to improved outcomes for partners [6].

Lazarus and Folkman's [15] theory of stress has been applied in diverse healthcare research settings and continues to influence the most current theory and research on coping. The authors' [15] contextual and cognitive model suggests that coping focused on problem resolution is more adaptive than coping focused on emotion. However, the dynamic aspects of their theory imply that differing coping styles may be appropriate depending on whether utilized at the onset of

a stressful event or later, and upon the person's appraisal of the situation and of their resources. When faced with acute stresses with little perceived control over outcomes and high levels of uncertainty, emotion-focused coping may be more effective, allowing reductions in distress and increases in support. The initial reactions to a partner's impending CABG surgery may be most characterized by emotional coping [15, 16], to include distancing, self-control of emotion, escape/avoidance, accepting responsibility, and confrontive coping. However, successful adaptation post-surgically requires active problem-focused coping efforts, as well. Folkman and Moskowitz [17] reviewed diverse research suggesting that social support coping is not just emotion focused, but has an important problem-solving component, as does positive reappraisal coping. Such problem-focused coping, broadly defined to include positive reappraisal, meaning-focused, and social support aspects, may be difficult for older female spouses in a medical environment that may encourage passivity and escape or avoidance patterns. Subsequent analyses of coping have suggested another distinction, that between disengagement coping reactive to a stressor and engagement coping via initiation of adaptive problem-solving [18–20]. Thus, it may be useful to explore what are the characteristics of spouses and the situations associated with use of reactive emotion-focused coping or adaptive problem-focused coping, and whether there are differences in the use of coping associated with age variations among older female spouses.

Wagnild and Young's Resilience Scale (RS) [21] was developed to assess five themes found in interviews with older women who had adapted successfully to a major life event: (a) equanimity, (b) perseverance, (c) self-reliance, (d) meaningfulness, and (e) existential aloneness. The RS has shown validity in several studies of older women adjusting to loss [22, 23]. While resilience is sometimes treated as if it was a personality trait, its original definition suggests it is composed of specific skills and strategies which can be taught and strengthened [22]. The resilient woman's emotional balance, healthy independence, and ability to find positive meaning in stressful circumstances would likely facilitate higher levels of reported problem-focused coping, as well as adaptive flexibility.

Spouses' perceptions of life-change stress and social support may affect emotional distress and, therefore, ways of coping [14]. Women who report more life-change stress or less social support may have difficulty mobilizing adaptive problem-focused coping due to greater perceived situational demands and less perceived personal resources. These women may spend more effort on reactive emotion-focused coping in order to achieve emotional balance and favorable perceptions.

This study aims to describe patterns of coping among older female spouses dealing with a partner's CABG surgery and the relationships of these patterns with life-change stress, cognitive appraisal of CABG surgery, resilience, social support, demographic factors, and aspects of the surgery. Based on these theoretical frameworks and prior research [14, 24], it is hypothesized that women who are resilient and report higher levels of social support, fewer competing life stresses, and more favorable appraisal of the stressful circumstance of

CABG will report greater use of adaptive problem-focused coping with a spouse's CABG event and less use of reactive emotion-focused coping.

2. Materials and Methods

2.1. Design. A retrospective, descriptive, and exploratory survey design was used, with questionnaires distributed to a convenience sample of older female spouses of male post-CABG partners. The study was reviewed and approved as exempt by the appropriate hospital and university Institutional Review Boards.

2.2. Setting and Sample. Ten clinical sites were recruited from two midwestern hospital systems in the USA. Sites included two cardiovascular surgery offices, three cardiac rehabilitation facilities, two surgical preteaching departments, and three post-surgical units. The site of origin of surveys was not recorded. Site staff distributed survey packets to female spouses of patients who had undergone CABG within the previous 3 months. All eligible spouses, those of 55 years of age or older, and able to speak, read, and understand English, were provided an informational letter, along with the survey packet, which explained the study and its anonymous nature. Consent was presumed if the spouse mailed back the survey packet in the stamped and addressed envelope provided with the packet. A total of 106 surveys were distributed by research sites, and 96 usable surveys were completed and returned, yielding a 91% response rate. Due to the anonymous nature of the study, there is no identifying personal data for those who completed the survey nor is there any demographic data for those who declined.

2.3. Measures. Demographic information included participant's age, ethnicity, religious activities, educational level, number of years married, number and location of children, employment status, family income, comprehensive health insurance, personal illnesses in the past year, CABG aspects of timing and presurgical education, financial strain, and partner's cardiac history. Life-change stress was evaluated using the Family Inventory of Life Events (FILE), a measure of how many diverse family events and changes have occurred during the previous year [14, 25]. For this sample, a FILE item asking about respondents' difficult pregnancy in the past year was omitted. Cognitive appraisal of partner's surgery was measured by the validated spouse perception scale (SPS) [26, 27]. The SPS provides a total score reflecting how favorable spouses' attitudes are toward their partner's recent surgery. Resilience was measured by total score on the Resilience Scale (RS) [21, 23]. The social support index (SSI) yields a total score measuring respondents' evaluation of family integration and support in the community [28, 29]. Reliabilities observed for all these measures in the present sample were acceptable (Cronbach's alphas .78 to .94) and comparable to values reported in prior studies noted above.

The ways of coping questionnaire (WCQ) [16] asked spouses to respond according to how they coped with their

partners' CABG, during and since surgery. The WCQ provides average scores (ranges from 0 to 3, corresponding from "not used" to "used a great deal") for each of eight coping scales. In this sample, reliabilities of these coping scales were acceptable for research purposes (Cronbach's alphas .49 to .72). Folkman and Lazarus [16] have indicated that reliabilities may trend lower for these scales because a few items within a coping scale may be very highly rated, while others are rated minimally or not at all.

Folkman and Lazarus provide succinct descriptions of the content of the coping scales, which have been validated in research on older adults, as well as caregivers and family members of those with acute or chronic illness [30–33]. Planful problem solving refers to deliberate problem-focused efforts, while seeking social support represents the pursuit of tangible, informational, and/or emotional support from others. Positive reappraisal refers to efforts to create positive meaning and to use a religious dimension in coping, while self-control coping involves efforts to regulate or moderate one's feelings and actions. Distancing coping involves cognitive efforts to detach from or minimize the significance of the stressful situation, while escape-avoidance refers to wishful thinking and behavioral escape from problem circumstances. Confrontive coping takes the form of aggressive action and risk-taking in response to stress, while accepting responsibility involves a focus upon one's own role or responsibility and efforts to atone or make things right [16]. Both confrontive and accepting responsibility scales include items pertaining to strong emotions of anger or guilt. Recent work has resulted in multiple reanalyses and rescoring of the WCQ, and previous authors suggest that the WCQ's structure should be reexamined for populations under investigation [20, 34]. Therefore, the WCQ scales were factor analyzed in the current sample.

2.4. Data Analysis. Relationships among descriptive and demographic variables were examined depending on scales of measurement, via either Chi-squared analyses or one-way ANOVAs and independent sample *t*-tests (all with $P < .05$, 2-tailed). A MANOVA was conducted to assess differences in WCQ scores as a function of spouse age groups. Paired *t*-tests were used to ascertain significant differences among coping scores in the overall sample. In order to further describe and simplify broad patterns of coping in this particular sample, exploratory factor analyses of the eight coping subscales were conducted using principal components factoring and Varimax rotation. Relationships among coping factors and the predictor variables noted (FILE, SPS, SSI, RS) were assessed via 2-tailed bivariate Pearson correlations ($n = 96$). Pilot regression analyses were conducted to ascertain sets of variables predictive of ways of coping, as measured by factor scores. An original power analysis calculation determined a sample size of 61 would be sufficient to detect a Pearson correlation of .35 (2-tailed alpha of $<.05$) with a power of .80 [35–37]. In light of the descriptive and exploratory nature of this research, power was based on simple correlations, and regression analyses were considered exploratory and subject to replication. Calculations and statistical procedures were conducted using SPSS version 11.5.0.

3. Results

These 96 female spouses of CABG patients were mostly European-American, unemployed, of modest income, and at least high school educated, with over 25% reporting some college-level education. Marital relationships were long term, and most spouses had at least one child living nearby. Mean age was 65.8 years, with a range from 55 to 81 and only 7 spouses over 75 years of age. The sample showed approximately 33% either older than 70 years, 62 to 70 years, or younger than 62 years, and these cutoffs were used in subsequent analyses in order to maintain similar numbers of subjects among the age groups. Most spouses denied financial hardship due to CABG, reported comprehensive health insurance, noted relatively few illnesses of their own in the past year, and reported high levels of religious involvement. Most spouses reported that partners had not experienced a prior myocardial infarction or CABG surgery. Approximately 50% of spouses reported one week or more lead time between being informed of the need for surgery and the surgery itself, while 30% of spouses reported urgent/emergent surgeries, those with a day or less elapsing between identified need and the surgery itself. Survey data did not include clinical rationales for variations in surgery lead time. Nearly 50% of spouses reported pre-surgical education. Table 1 presents demographic data and Table 2 presents stress, coping, and personality data for the sample.

Age, analyzed for the three age groups noted above (over 70 years, 62 to 70 years, under 62 years), showed significant relationships with employment status, household income, and religious participation. Oldest women, compared to the two younger groups, reported much less employment, part or full-time (6%, 32%, and 77% employment, respectively; chi-square (4 df) = 30.6, $P < .001$) and higher rates of at least weekly church attendance (97%, 68%, and 60%, respectively; chi-square (10 df) = 22.9, $P < .05$). The older groups, compared to the youngest, reported lower average household income (\$28,971, \$34,677, and \$51,452, respectively; $F(1,93) = 10.78$, $P < .001$). Age was not related to reported comprehensive health insurance coverage or financial strain.

Women reported significant differences among means for the eight WCQ ways of coping scales, which are presented in Table 2, from most used to least. Paired-observation *t*-tests indicated statistically significant differences ($P < .02$) for all pairs of WCQ scales, with the exception of differences between confrontive and escape-avoidance coping, and between seeking social support and planful problem-solving coping. The means for positive reappraisal, planful problem-solving, and seeking social support were notably higher than the means for other ways of coping, while confrontive, escape-avoidance and accepting responsibility coping were notably lower, with means below .5 on the 3-point rating scale. The WCQ scale scores did not vary significantly among age groups, nor did they show any significant correlations with actual age.

An exploratory factor analysis on the WCQ coping subscales extracted two factors with eigenvalues >1.0 , accounting for 70.6% of total variance. The first, accounting for 57.4% of total variance, had rotated loadings greater than .74 for

TABLE 1: Spouses' demographics ($n = 96$).

| Demographics | Mean | SD | Number | Percentage |
|--------------------------------------|------|------|--------|------------|
| Age | 65.8 | 7.2 | | |
| <62 years | | | 31 | 32.3 |
| 62 to 70 years | | | 31 | 32.3 |
| >70 years | | | 34 | 35.4 |
| Income | | | | |
| <\$20,000 | | | 16 | 16.6 |
| \$20,000–\$29,999 | | | 31 | 32.3 |
| \$30,000–\$49,999 | | | 26 | 27.1 |
| >\$49,999 | | | 23 | 24.0 |
| Race/ethnicity | | | | |
| European-American | | | 96 | 100.0 |
| Employment status | | | | |
| Full time | | | 15 | 15.6 |
| Part time | | | 15 | 15.6 |
| Not employed | | | 52 | 54.2 |
| Item omitted | | | 14 | 14.6 |
| Educational level | | | | |
| High school or less | | | 74 | 77.0 |
| Some college | | | 11 | 11.5 |
| College degree or above | | | 11 | 11.5 |
| Children | | | | |
| Yes | | | 92 | 95.8 |
| No | | | 4 | 4.2 |
| How many children | 3.7 | 2.9 | | |
| Children nearby | 2.4 | 2.0 | | |
| Years of marriage | 40.5 | 13.4 | | |
| Comprehensive health insurance | | | | |
| Yes | | | 91 | 100.0 |
| Missing data | | | 5 | |
| Financial hardship due to CABG | | | | |
| Yes | | | 34 | 35.4 |
| No | | | 62 | 64.6 |
| Religious attendance Frequency | | | | |
| Daily | | | 18 | 18.7 |
| Weekly | | | 55 | 57.3 |
| Monthly or less | | | 23 | 24.0 |
| Presurgical education | | | | |
| Yes | | | 45 | 46.9 |
| No | | | 51 | 53.1 |
| Number of illnesses in the past year | 1.4 | 1.3 | | |
| Days waiting for CABG | | | | |
| Less than 1 day | | | 28 | 29.5 |
| 1 day to 1 week | | | 20 | 21.0 |
| >1 week | | | 47 | 49.5 |
| Missing data | | | 1 | |

TABLE 2: Stress, personality, and coping data.

| | Mean | SD | Range |
|---------------------------------------|-------|------|----------|
| Stress and personality measures | | | |
| FILE (life-change stress) | 5.4 | 4.6 | 0–20 |
| Spouse's perception scale (appraisal) | 178.9 | 21.3 | 122–229 |
| Resilience | 139.4 | 20.7 | 54–175 |
| Social support index | 51.2 | 8.4 | 27–68 |
| Ways of coping (WCQ raw scores) | | | |
| Positive reappraisal coping | 1.35 | .59 | .14–3.00 |
| Planful coping | 1.19 | .60 | .17–2.67 |
| Seeking social support coping | 1.19 | .58 | .00–2.50 |
| Self-controlling coping | 1.02 | .59 | .00–2.71 |
| Distancing coping | .74 | .46 | .00–2.17 |
| Confrontive coping | .48 | .45 | .00–2.33 |
| Escape-avoidance coping | .46 | .35 | .00–1.38 |
| Accepting responsibility coping | .33 | .53 | .00–2.25 |

reactive coping based on its mixture of strong emotional reactions turned inward (guilt) or outward (anger) coupled with disengagement coping, such as escape/avoidance or suppressed responding. The second factor, accounting for 13.2% of total variance, had loadings greater than .64 for seeking social support, positive reappraisal, and planful-problem solving coping. This factor was termed adaptive coping based on its loadings for positive reappraisal, seeking of social support, and planful problem-solving, all suggesting an engaged instrumental approach to the CABG experience. Factor scores were calculated and used in subsequent analyses.

Life-change stress (FILE), spouse appraisal of the CABG experience (SPS), resilience (RS), and social support (SSI) were all significantly correlated. Spouses with more life-change stress showed lower resilience scores, less perceived social support, and less favorable appraisal of the CABG experience. Resilience showed positive associations with perceived social support and favorable appraisal of the CABG surgery. Perceived social support and favorable appraisal were positively correlated. Reactive coping showed no significant correlations with resilience, social support, life stress, or favorable appraisal of the surgical experience. However, adaptive coping was associated with greater resilience, more social support, and more favorable appraisal. Table 3 presents correlations and significance levels.

Stepwise multiple regressions then examined best predictors of reactive and adaptive coping. Variables entered into each analysis included FILE, RS, SPS, SSI, demographic measures, time elapsed between CABG and survey completion, time between acute diagnosis and surgery, participation in pre-surgical education, spouses' illnesses in the past year, and spouses' religious participation. Demographic measures included age, years of marriage, educational level, income, number of children, and number of children living nearby. Stepwise regression for reactive coping yielded a single predictor, time between acute diagnosis and CABG surgery, with an adjusted R^2 of .050 ($F(1, 93) = 5.92, P < .05$) and a standardized Beta of .245 for the single predictor. Having

escape/avoidance, confrontive, accepting responsibility, self-controlling, and distancing coping. This factor was termed

TABLE 3: Correlations among stress and coping measures.

| | CABG appraisal | Resilience | Social support | Reactive coping | Adaptive coping |
|--------------------|----------------|------------|----------------|-----------------|-----------------|
| Life-change stress | -.38*** | -.37*** | -.34*** | .01 | .02 |
| CABG appraisal | | .46*** | .35*** | .00 | .21* |
| Resilience | | | .39*** | -.05 | .26** |
| Social support | | | | -.06 | .20* |

All values are 2-tailed Pearson correlations ($n = 96$).

* $P < .05$.

** $P < .01$.

*** $P < .001$.

spent more time anticipating the surgery predicted greater reported use of reactive coping. Stepwise regression for adaptive coping yielded three predictors in the final equation, with an adjusted R^2 of .202 ($F(3, 91) = 8.94, P < .001$). Fewer children (standardized Beta = $-.343$), more frequent religious participation (standardized Beta = $.238$), and greater resilience (standardized Beta = $.314$) were predictive of greater use of adaptive coping.

4. Discussion

As expected from the theoretical frameworks and conceptual definitions, spouses with more resilience reported more social support, more positive appraisal of the surgical experience, more use of adaptive coping, and less life-change stress. Contrary to expectation, more emotion-focused coping, as measured by the reactive coping factor and WCQ subscales, showed minimal relationship with resilience, social support, or life-change stress. The spouses demonstrated a distinct profile of coping, reporting the least use of ways of coping within the reactive coping factor and the most use of ways of coping within the adaptive coping factor. These coping factors are not identical to the emotion-focused versus problem-focused distinction, but are consistent with Folkman and Moskowitz's [17] review of coping and other recent reviews of the coping literature [18]. As Lazarus and Folkman [15] have suggested, and has recurred in writings and research since [17–19], coping is indeed a flexible process, wherein all these ways of coping have healthy roles, as well as less healthy ones.

This view of spouses' coping is supported by regression analyses for each coping factor. The only significant predictor of reactive coping was more time reported between diagnosis and surgery. This result suggests that more time spent in a holding pattern, uncertain about what could be done to resolve problems, is associated with greater use of reactive coping. In contrast, adaptive coping was strongly associated with resilience. Having more children predicted less adaptive coping, perhaps due to how a mixture of social demands and social support provided by a larger family may supplant intentional adaptive coping efforts. Finally, as suggested by Folkman and Moskowitz's [17] review of coping and the contributions of such researchers as Pargament [38], amount of religious participation was predictive of more use of adaptive coping.

This study is limited by its retrospective approach, though Folkman and Moskowitz [17] suggest that such an approach

may allow more understanding of the spouses' narratives of how they perceived and went through the stressful events. This study did not have measures of mental health outcomes, such as anxiety or depression, though the dynamic nature of coping suggests that such mental health issues may guide the next round of coping processes rather than representing fixed endpoints. Nonrandom sampling poses a greater challenge, in that those sampled may have been better known by staff and had partners more involved in cardiac followup. In addition, this sample may have excluded those with surgical experiences that were devastating, or those most noncompliant with or alienated from the healthcare system. In particular, those with spouses who did not survive the acute cardiac events were still receiving acute care for other emergent medical problems or were transferred to residential care would be less likely to have been recruited for this study. Measures within the study did not include any objective clinical data on how complex and difficult the CABG experiences were. The current sample did not have a good representation of the oldest-old group of aging women, those 80 or older [39], with only a small percentage of spouses older than 75. The projected growth of that segment of the older female population in future decades suggests an ongoing need for further research on how the most senior women successfully cope with critical family illnesses.

These results suggest that care for older female spouses after partners' CABG surgery needs to address life event stresses arising from the surgery itself or from other life areas, to educate the spouses concerning social support resources, to facilitate assertive problem-solving, and to suggest resources for rehabilitation and wellness that may facilitate positive reappraisal and a sense of meaning. Nursing staff should accept and validate expressions of reactive coping during the initial diagnosis and during circumstances that force families to cope with delay or uncertainty. Spouses who use the extremes of reactive coping may take on undue guilt or responsibility, may more aggressively confront the healthcare system, may suppress or deny emotions more rigidly, and may show avoidance of the surgical situation. These patterns are part of reactive coping and do not limit or preclude successful use of adaptive coping. Linnarsson et al. [40] have conducted a metasynthesis of qualitative research on the needs and experiences of critically ill or injured patients' significant others (SO), defined to include "all persons close and significant to the patient. . ." [40]. They noted within diverse studies five content themes, one of which (uncertainty and emotional "roller coaster") captures

the sense of reactive coping: an “initial chaotic time and the uncertainty led to a strong feeling of being powerless and not being able to do anything to help . . . keeping it together trying to avoid breaking down with emotion, acting out . . . some talked about distancing themselves to bear the pain” (3104). Content within their other four themes aligned with aspects of resilience, social support, and adaptive coping: (a) balancing hope and reality, (b) protecting and guarding the loved one, (c) alliance with caregivers, and (d) social network support. The adaptive versus reactive coping dimensions in the current research thus appear parallel to the experiences of diverse significant others close to a critically ill person.

Adaptive coping can be supported by nursing interventions that include mobilizing specific resources for problem-solving, encouragement of social support in order to maintain emotional stamina, and careful attention to the spouse's efforts to reappraise and find meaning in an extremely demanding experience. Qualities of resilience overlap with components of adaptive coping and together suggest a set of skills and strengths that warrant attention during and after the surgical experience. Staff may do well to accept and normalize reactive coping, even in its extreme forms, while providing opportunities, encouragement, and support for spouses' use of adaptive coping skills. As Linarrson et al. [40] observe, “significant others face an overwhelming and emotionally challenging situation, and they need to be seen and heard by the caregivers” (3109–3110). Staff may encourage resilience and adaptive coping via uncovering spouses' previous successes coping with extreme disruption, mobilizing use of religious resources, and supporting qualities of emotional stamina, courage, and adaptability in stressful circumstances [22, 23].

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Research Article

Assessment of Ethical Ideals and Ethical Manners in Care of Older People

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The aim of this study is to establish structured clusters and well-defined ontological entities (nodes) describing ethical values as both ideal and opportunity for ethical manner as perceived by the caregiver. In this study, we use Bayesian Belief Networks (BBNs) to analyse ethical values (ethos) and ethical manners in daily work with older people. Material is based on questionnaire data collected by the instrument for the self-assessment of individual ethos in the care of older people (ISAEC) in spring 2007 in a municipality in Western Finland. This study is unique in its kind, both concerning the selected approach and methodological questions. BBNs have not been used significantly in nursing research, nor are there any studies that examine the ethical possibilities with focus on the probable effects upon changing conditions.

1. Introduction

Ethical discussions between caregivers affect the quality of the older person's care, and Ågren Bolmsjö et al. [1] have found that ethical decision-making supports ethically good care of patients. Berggren et al. [2] associate the discussion of ethical values with a deeper level of communication, and in order to achieve depth in such a dialogue, an ethical code and a set of ethical values which penetrate caring are needed. Awareness of such ethical values equips caregivers with a freedom and strength to make conscious decisions to do well and to do right in a given care situation. A caregiver's ability to do well and do right is strengthened in the dialogue between caregivers and other health care professionals [3].

In this study, we use Bayesian Belief Networks [4, 5] (BBNs) to analyse ethical values (ethos) and ethical manners in daily work with older people. The advantage with BBNs is the possibility to use and compute with symbolic (symbolic

data has no per se measurable or comparable values), as opposed to numeric or nominal (. . . 1, 2, 3, 4, 5 are nominal not to be seen as numerical . . .), data. Linear regression and comparable methods require numeric data for its computations. Data used in this study are nominal in the answers to questions in the questionnaire, but inherently symbolic when arriving at ethical data and classifications of ethical manner. Further, BBNs are able to manage stochasticity and uncertainty and can work simultaneously with objective and subjective probabilities in one and the same model.

Material is based on questionnaire data collected by the instrument for the self-assessment of individual ethos in the care of older people (ISAEC) in spring 2007 in a municipality in Western Finland [6]. The study is based on a caring science perspective, and caregivers' ethical values and ethical manner which are evaluated in the study have been interpreted to the theory of caritative caring ethics [7] and to previous research on ethics in the care of older people [8–13]. The caring science

perspective appears in the statements of the questionnaire, and in the concept, which are given the clusters and nodes, generated with BBN.

Biostatistics or, generally speaking, statistics as used in the care domain is indeed strictly statistics. “Statistic inference” is not logic inference but ad hoc conclusions derived from statistical observations and analysis. Such conclusions are not expressed in any logical language but still within the statistical machinery. However, health and social care involving observations, assessments, and decision-making mean that somewhere along the line *statistics moves over to logics*.

Logical entailment \vdash is a relation between premises and conclusions. It is syntactic reasoning as related to its semantic counterpart, namely, logical satisfaction \models . We will illuminate our epistemology with syntactic entailments, where the choice of a specific logic, first-order or otherwise, is not relevant as we are providing a complete ethical ontology in this paper.

1.1. Theoretical Framework. In the theory of caritative caring ethics [14] and in the previous research on ethics in caring, related to the care of older people can we see, among other, values as dignity, [10, 15–17] integrity, [11, 16, 18–20] autonomy and participation, [10, 16, 17, 21], respect and safety [13, 20, 22, 23]. We can also find different explanations about caregivers’ possibilities to act in an ethical manner in the daily work with the older persons. It is not self-evident that ethical values of the caregivers turn into ethical manners in the daily work, and we have to state that *a good intention goes wrong* [11], and the caregiver encounters different ethical problems and challenges that need to be resolved. Often there is not one solution to the problem, rather, many different solutions. The essence of caring is to alleviate the patient’s suffering and promote health and wellbeing. Eriksson [24] described caring ethics in terms like love and mercy, caring relationship, human dignity and respect, which accordingly affects human beings’ decisions and choices in a specific manner [7, 24–26]. The *caring communion* is the deepest motive for every kind of caring. A professional caring relationship implies a responsibility of caregiver vis-à-vis the patient he/she takes care of.

An ethically aware caregiver strives to invite the patient into a caring relation that mediates strength as well as respect for the integrity and wholeness of the human being [15]. An ethically aware caregiver also strives to “do well,” “do right,” and “take responsibility,” and he/she wanted to show the patient respect [9].

To act ethically in an ontological sense is not always related to time. Acting ethically exists in the moment when goodness becomes a conscious choice for the caregiver. To act ethically in the daily work requires a professional freedom, enabling caregiver to choose and decide just in the moment when caregiver and patient meet each other. This kind of freedom goes behind routines and stereotypical behaviours and thereby promotes unique meetings.

1.2. Aim. The aim of this study is to establish structured clusters and well-defined ontological entities (nodes) describing

ethical values as both ideal and opportunity for ethical manner as perceived by the caregiver. This additionally provides an enlargement and enrichment of the underlying ethical assumptions about ethical values and the dynamics in spectra of caregiver ethical manner. An additional objective is to evaluate the effect of fixing nodes to certain assessments levels, in order to see how other nodes are affected in themselves and from the viewpoint of the entire cluster. This in turn contributes to knowledge elicitation and epistemological enhancement with respect to the ontological framework.

This paper focuses on the following questions:

- (1) (ontological question) which are the main patterns involving ethical value and ethical manner emerging from this study, given the underlying structural entities and dynamical ethical values and manners?
- (2) (complementary epistemological question) which are the various types of conditional changes of ethical values and their related ethical manners that appear when fixing nodes to particular values and thereby clusters to specific characters?
- (3) (societal impact) how will this elicited knowledge in the end affect daily care of older people and as viewed from an ethical perspective?

2. Method

2.1. Participants. Caregivers from 10 units in the care of older persons were invited to participate in the study. Three units represented Home Care, four units Nursing Home Care, and three units Long-Term Care. A majority ($n = 80$) of the informants worked within Nursing Home Care or within Long-Term Care, whereas the remaining informants ($n = 25$) worked within Home Care.

A majority of the informants had a vocational degree, for instance, registered nurses and practical nurses. Totally, 24 caregivers had attended shorter courses according to older educational programs, such as courses for care assistants, and six of the informants lacked formal competence for their work.

2.2. Data Collection. Data were collected with an instrument called “*the instrument for self-assessment of individual ethos in care of older persons*” and redact ISAEC. Totally, the instrument consists of 58 statements. Twenty-eight statements refer to ethical values as ideals, and 30 statements refer to the possibilities to act in an ethical manner, in the daily work with the older person. A total of 110 questionnaires were handed out by leaders from each unit. Totally, 105 questionnaires were returned, which gives a response rate on 95%.

Total data consist of 6900 observations. Statements in ISAEC instruments were allocated into five groups, as follows: Group I = individual care, Group II = dignified care, Group III = safety care, Group IV = caring communion, and Group V = closeness or/and distance.

The participants were asked to answer the questionnaires by choosing the alternative which best responded to their opinion. The alternatives were stated as follows: not at all

agree = 1, partly agree = 2, sometimes = 3, nearly agree = 4, and totally agree = 5 (ethical values as ideals) and never = 1, nearly never = 2, sometimes = 3, mostly = 4, and always = 5 (ethical manners).

These alternatives were textually presented so that the attached numbering was only intended as an index for that particular alternative and not a gradation. In other words, the instrument aims at presenting the alternatives as symbols and not as numerical values. However, as numbers 1–5 were visible in the instrument, it can be expected that the set of alternatives was seen as an ordinal scale, so that, for example, “sometimes” is *before* “mostly,” but there is no distance measure between the two. This is indeed the main reason why we cannot compute with 1–5 as numbers, but rather as symbols in an ordinal scale, and this is why computing with conditional probabilities in Bayesian networks is very suitable.

2.3. Data Analysis

2.3.1. Conditional Probabilities and Bayesian Networks. We use Hugin as our tool for Bayesian network generation based on data. Learning from data by Hugin creates a network of nodes connected according to respective conditionalities between nodes. For a higher level of information, clusters of nodes can be created. Clustered nodes are then also linked by conditionalities between nodes.

The structure learning algorithms in Hugin are based on making dependence tests that calculate a test statistic which is asymptotically chi-squared distributed assuming (conditional) independence. If the test statistic is large for a given independence hypothesis, the hypothesis is rejected; otherwise, it is accepted. The probability of rejecting a true independence hypothesis is given by the level of significance, which was selected to be 0.05.

Several methods, including numerical, logical, and probabilistic ones, have been proposed to manage uncertainty in decision-support systems. The probabilistic approach with Bayesian networks are appealing as they capture a computational view of conditional probabilities, which is particularly useful in presence of questionnaires with interdependent questions and using symbolic or ordinal values.

Let $P(A, B)$ be the joint probability for A and B . Then, the conditional probability is defined as $P(A | B) = P(A, B) / P(B)$. This then gives the expression $P(A, B) = P(A | B)P(B)$ for joint probabilities with dependent variables.

The event A is said to be *conditionally independent* of event B if $P(A | B) = P(A)$, that is, whenever $P(A, B) = P(A)P(B)$.

The previous formulas are used to arrive at Bayes' rule $P(A | B) = P(B | A)P(A) / P(B)$ which is the most important rule used and manipulated in Bayesian networks. Bayes' rule makes it possible to calculate conditional probabilities $P(A | B)$, once the opposite conditional probability $P(B | A)$ is known together with the probabilities for the individual events A and B .

The Bayesian network notation for the probability situation $P(A, B) = P(A | B)P(B)$ is depicted as



indicating that B is conditional to A . Similarly, $P(A, B) = P(B | A)P(A)$ is depicted as

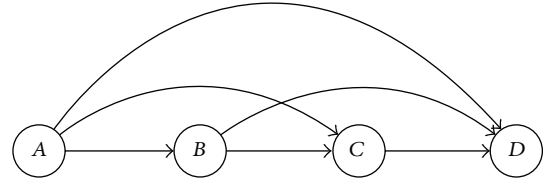


indicating A conditional to B . Given Bayes' rule, it is then clear that the direction of the arrow is interchangeable depending on the conditional context.

For several nodes, we then need to consider all pairs of conditional probabilities, that is, for the joint probability

$$P(A, B, C, D) = P(A)P(B | A)P(C | A, B)P(D | A, B, C). \quad (1)$$

We have the depiction



In the most simple cases, events are two valued, and we may, for example, write either $A = 0$ or $A = 1$. A probability like $P(C = 1)$ is then computed as

$$P(C = 1) = \sum_{a \in \{0,1\}} \sum_{b \in \{0,1\}} \sum_{d \in \{0,1\}} P(A = a, B = b, C = 1, D = d), \quad (2)$$

and a conditional probability like $P(A = 1 | C = 1)$ is computed as

$$\begin{aligned} P(A = 1 | C = 1) &= \frac{P(A = 1, C = 1)}{P(C = 1)} \\ &= \frac{\sum_{b \in \{0,1\}} \sum_{d \in \{0,1\}} P(A = 1, B = b, C = 1, D = d)}{P(C = 1)}. \end{aligned} \quad (3)$$

In the aforementioned we depict the use of binary data only. Clearly, we can work with more than just two classes of events. In this study, we work mainly with the alternative set $\{0, 1, 2, 3, 4, 5\}$, and conditionalities like $P(A \in \{3, 4, 5\} | B = 4)$ can be computed for tables in the Results section.

The learning algorithm, as implemented in Hugin, finds the appropriate and correct conditionalities given data. This then creates the Bayesian Belief Network (BBN), where the interconnection defines the structure of the network. This structure and network identification capability is one of the significant advantages of BBN developments. A *cluster* is

TABLE 1: Cluster I: Dignity.

| | | Distribution function for Cluster I (percent) | | | | | |
|----|--|---|------|-----|---|---|---------|
| | | 5 | 4 | 3 | 2 | 1 | Missing |
| F4 | Human love and mercy | 88,2 | 9 | 2,9 | | | |
| C5 | Moments of peace | 94,3 | 5,7 | | | | |
| E2 | To see the needs of the older person | 85,7 | 10,5 | 1 | | | 2,9 |
| B1 | Respect the needs and wishes of the older person | 87,6 | 8,6 | 1,9 | | | 1,9 |
| E4 | Caring community | 87,1 | 12,4 | 0,5 | | | |
| C2 | Encourage the older persons to utilize their own resources | 85,7 | 10,5 | 2,9 | | | 1 |
| A2 | To respect the equal value of each older person | 94,3 | 2,9 | 1 | | | 1,9 |

a subset of entities, so that, on the one hand, no entity in this subset is conditionally dependent with any other entity outside that cluster, and, on the other hand, there are no further subclusters within that cluster. We may also speak of *independent* clusters, to further underline that such clusters with no conditional dependency to their outside world are *molecular*.

2.4. Findings. Results are polarized, on the one hand, by *ethical values in the daily care with older people*, and, on the other hand, by *possibilities to act in an ethical manner in the daily care with older people*. However, ethical value and possibility are not complementary or mutually exclusive but rather appear as valuation domains for enabling projection and transformation of given value criteria.

From ethical point of view, good care refers in particular to *dignity, participation, safety, caring community, and closeness and distance*, where the latter is concerned mostly with aspects of possibility and the others project to both ethical value and possibilities. This enables, for example, the concept of dignity to be seen as fundamentally ethical at the same time as consideration of dignity becomes a possibility. Similar multimodality with respect to ethical value and possibility can be said about the other concepts, respectively, participation and safety and caring community.

Concepts for ethical value and possibility are further characterized by underlying nodes or entities in clusters related to these concepts, thereby also the entities being members of specific clusters, and conditionalities between these entities.

Among all 58 statements, it turned out that ten statements became one-node clusters; that is, these statements did not show any conditionality with any other statements. These statements were left out of further analysis, since no matter how the dynamics within such a statement is further analysed, it has no effect on any other statement. Indeed, a main objective of this paper is to analyse situations within clusters, where fixation of particular ordinal values for one statement may affect dynamics concerning sibling statements in that cluster. Note that we may speak of sibling nodes, even if it is seldom clear where parent nodes reside in clusters. This is given by the fact that conditionality is really not “directed,” and “changing directions” of conditionalities is done by Bayes’ rules.

Structure identification by Hugin also resulted in a number of two-node clusters. Interesting among these clusters were that clashing and enforcing them into one node and restructuring all the remaining nodes provided such two-node clusters to become singleton clusters, in all cases expect for one case where that singleton node become integrated into a larger cluster. This is a motivation for leaving also two-node clusters outside further analysis.

The number of remaining clusters is 9, and the number of nodes in those respective clusters varies from 3 to 7. Among these 9 clusters, 4 clusters contain ethical value statements, and 5 clusters contain possibility statements. The interesting next step is now the semantics of these 9 clusters and their nodes. What is the *name* of the cluster, and what is the *interpretation* of that name? A major part of this Results section is to analyse what happens when certain nodes in clusters are frozen to particular ordinal values. The Bayesian network then recomputes the distribution functions for the other nodes, and the recomputation is enabled by the conditional probabilities. This enables a number of interesting what-if analyses, like if E2, E4, and C2 are fixed at 4, that is, the distribution functions for all these nodes become 100% at ordinal value 4, how does the “move” or “shift” of the function is dynamic for the other nodes?

2.5. Ethical Values in the Daily Care with Older People

2.5.1. Cluster I: Dignity. The cluster *dignity* consists of seven nodes or entities. There are small differences between the agreement levels of respective informants. About 85–94 percent of the informants totally agree with all seven statements. In Table 1, we have the distribution function for the cluster *dignity*.

Nodes where level “4” responses in percentage exceed 10 are selected for fixation to a response rate of 100%. These respective fixations are then compared with the shift in response rates for the other nodes, as well as the way they shift in response rates according to the underlying conditional probabilities model of the network.

In order to see this more precisely, let node E2, *to see the needs of the older person*, be fixed at response level “4” = 100%. The influence on node E4, *caring community*, is a 17% shift of level “5” responses to level “4” responses, and on node C2,

TABLE 2: Effects on distribution function when E4 fixed to “4” = 100%.

| | | 5 | 4 | 3 | 2 | 1 | Missing |
|----|--|--------|-------|------|---|---|---------|
| F4 | Human love and mercy | −11,51 | 1,91 | 9,59 | | | |
| C2 | Encourage the older persons to utilize their own resources | −10,5 | −8,06 | 12,1 | | | 6,46 |
| A2 | To respect the equal value of each older person | −19,3 | 4,84 | 1,35 | | | 13,11 |

TABLE 3: Effects on distribution function when C2 fixed to “4” = 100%.

| | | 5 | 4 | 3 | 2 | 1 | Missing |
|----|----------------------|-------|-------|------|---|---|---------|
| F4 | Human love and mercy | −9,03 | 11,32 | −2,3 | | | |
| E4 | Caring community | 8,15 | −9,5 | 1,36 | | | |

encourage the older persons to utilize their own resources, the effect is an increase of level “4” responses by 18% and level “3” responses by 16%.

Further, for node E4, *caring community*, fixed at level “4” = 100%, node F4, *human love and mercy*, decreases at level “5” by 10% to level “3,” node C2, *encourage the older persons to utilize their own resources*, decreases at level “5” by 10% and at level “4” by 8% with an increase at level “3” by 12% and increase on missing data, that is, “cannot say” data, by 6%, and for A2, *to respect the equal value of each older person*, there is decrease of 13% from level “5,” and as this node had a rather low occurrence of missing data, it is notable how the portion of missing data increases as much as 13% (see Table 2).

Concerning node C2, *encourage the older persons to utilize their own resources*, changes due to conditionalities for node F4 and E4 are seen in Table 3.

2.5.2. Clusters II–IV. The following clusters are named *community* (cluster II), *safety* (cluster III), and *integrity* (cluster IV). In Table 6, we find the clusters and the named nodes for each cluster. We did not find any dynamical shift in the distribution functions after conditionalities for the nodes had been fixed in level “4” to 100%.

Based on these results, we can state that caregivers, participating in the study, agree that dignity, community, safety, and integrity are important ethical values, in order to guarantee an ethically defensible care, in care with older people.

The last cluster of ethical ideal was named integrity. The distribution function for this cluster is explained in Table 6.

2.6. Possibilities to Act in an Ethical Manner in the Daily Care with Older People. Five clusters describe the caregivers’ possibilities to act in an ethical manner, within their daily work with the older persons. The clusters are named as follows: *possibility for closeness and distance*, *community*, *dignity*, *safety*, and *participation*. The degree of coherence between the statements and the own opinions varies significantly between the informants.

A dynamical shift in the distribution functions, when conditionalities for respective node have been changed, can be found within all clusters. It is apparent that the shape of the clusters is affected as the underlying conditions and properties change, for example, with respect to change of caregivers,

TABLE 4: Cluster II: Community.

| | | Distribution function for Cluster II (percent) | | | | | |
|----|--|---|------|---|---|---|---------|
| | | 5 | 4 | 3 | 2 | 1 | Missing |
| A4 | Caring community | 94,3 | 5,7 | | | | |
| B3 | Listen to the wishes of the older person | 85,7 | 10,5 | 1 | | | 2,9 |

TABLE 5: Cluster III: Safety.

| | | Distribution function for Cluster III (percent) | | | | | |
|----|---------------------------------------|--|----|---|---|---|---------|
| | | 5 | 4 | 3 | 2 | 1 | Missing |
| A3 | The experience of confidence | 99 | | | | | |
| E3 | Professionally caregivers make safety | 96 | 3 | | 1 | | |
| D3 | Knowledge make safety | 79 | 13 | | | | 2 |

as new personnel enter the unit, and the condition spectra change at the unit either for particular individuals or by individuals leaving and new patients entering. The changes obviously affect care intensity as a whole. Further, organizational and administrative aspects and/or changes may also have effect on ethical manner.

2.6.1. Cluster V: Possibility for Closeness and Distance. Cluster V consists of three nodes: *sensitivity*, *professional approach*, and *a genuine interest in the quality of life of the older person*. The nodes are closely intertwined, and dynamics of the conditionality in respective nodes affects each other within the cluster. Fixation in one node implies adjustments of frequencies in the other nodes. Thereby changes like fixations at level “4” will imply downshifts in the other nodes towards levels “4” and “3.” Thereby, ethical manners, as caregivers’ *professional approach* and *interest for the older person*, will be important entities for upholding closeness and/or distance in the daily work with the older person (Table 7).

2.6.2. Cluster VI: Possibilities for Dignified Care. Cluster VI consists of six nodes (the nodes and the distribution function for the cluster are presented in Table 8).

For upholding dignified care, entities as *respecting the philosophy of life*, *creating a meaningful life*, and *continuously keeping the older patients informed on the phenomena of significance* for their health and wellbeing, will be of most

TABLE 6: Cluster IV: integrity.

| | | Distribution function for Cluster IV (percent) | | | | | |
|----|---|--|----|---|---|---|---------|
| | | 5 | 4 | 3 | 2 | 1 | Missing |
| D1 | The older person is unique with unique needs | 84 | 13 | 1 | | | 2 |
| B4 | Inviolability | 88 | 9 | 3 | | | |
| C3 | Be responsible for the safety of the older person | 89 | 6 | 2 | 2 | | 1 |
| C4 | Respectfully done nursing | 95 | 4 | 1 | | | |

TABLE 7: Cluster V: Possibilities for closeness and distance.

| | | Distribution function for Cluster V (percent) | | | | | |
|-----|---|---|----|----|---|---|---------|
| | | 5 | 4 | 3 | 2 | 1 | Missing |
| B51 | Sensitivity | 48 | 39 | 8 | 3 | | 2 |
| E51 | Professional approach | 47 | 38 | 10 | 2 | | 3 |
| C51 | A genuine interest in the quality of life of the older person | 34 | 45 | 14 | 3 | | 4 |

TABLE 8: Cluster VI: Possibilities for dignified care.

| | | Distribution function for Cluster VI (percent) | | | | | |
|-----|---|--|------|------|-----|---|---------|
| | | 1 | 2 | 3 | 4 | 5 | Missing |
| C21 | Respecting the philosophy of live of the older person | 52,4 | 31,4 | 10,5 | 1,9 | 1 | 2,9 |
| A21 | Observing the older person's dignity | 55,2 | 39,1 | 3,8 | 1,9 | | |
| B21 | Treating the older person as an adult person | 63,1 | 32,2 | 3,7 | | | 1 |
| E21 | Creating a meaningful life for the older person | 41,9 | 41,9 | 10,5 | | 1 | 4,8 |
| F21 | Continuously informing the older person | 27,6 | 44,8 | 18,1 | 3,8 | | 5,7 |

importance. As many as 18 percent feel that their possibilities to continuously inform the older about their health situation remain at level “3,” and 10 percent of the informants state that they “*sometimes*” have possibilities to respect *the philosophy of life* of the older person. About 16 percent of the informants feel they have limited possibilities to create a meaningful life for the older patients.

We shall see what most likely happens inside the cluster if we fix some of the entities at level “4” to be 100 percent. A dignified care seems to be dependent on caregivers’ attitude to the older patients. A fixation at level “4” for node B21 (*treating the older as an adult person*) will imply downshifts in nodes F21 (*to continuously inform the older person*), C21 (*to respect the philosophy of the life of the older*), and E21 (*to create a meaningful life for the older*).

The following example also reinforces the attitude of the caregivers as an important factor for opportunities to enable dignified care for the older persons. A fixation at level “4” for node E21 (*to create a meaningful life for the older*) downshifted nodes D21, A21, and B21, at level “3” about 4–19 percent (Table 10).

These two examples show how the attitude of caregivers makes distinctions about upholding the dignity of the older person in the daily work, and we can see the same tendencies with fixation at level “3” or “4” for the other nodes within the cluster.

2.6.3. Cluster VII: Possibilities for Participation. The cluster consists of seven nodes, where the nodes including *freedom* and *believing* the older person are entities that informants perceive as important entities to facilitate patient involvement in their own care. The distribution functions show that *ability for the patients to participate* in their own care is limited. The *caregivers’ desire to care for the same patient during a longer period, sharing moods with the older, and being humble when facing the older person* provide further dimensions for evaluations and enrichment as related to patients themselves given possibilities for participation. Making use of the older person’s resources and capacities is a real challenge, and on the basis of the results, it appears that caring is more about doing *for* than doing *with* the patient, that is, indeed being participative in these respects.

What happens within the cluster if a fixation at level “4” to 100% is done for some of the nodes in the cluster? Nodes A41 (*promote continuity and preservation in the care process as a whole*), F41 (*being emphatic and sharing the moods with the older person*), A11 (*support resources of the older patient*), G41 (*being humble while caring for the older person*), and D41 (*encourage participation*) being affected both upwards and downwards in the set of alternatives, as well as participation of the patient, are dependent on caregiver attitudes. The effects on distributions for respective nodes are described in Tables 11, 12, 13, and 14.

TABLE 9: Effects on distribution function when B21 fixed to “4” = 100%.

| | | 5 | 4 | 13 | 2 | 1 | Missing |
|-----|--|--------|-------|-------|------|-------|---------|
| D21 | The older person is treated respectfully regardless of health status | -2,2 | 3,21 | 0,28 | | | -1,29 |
| C21 | Respecting the philosophy of life of the older person | -6,53 | 8,63 | 0,63 | 2,05 | -0,26 | -2,61 |
| A21 | Observing the older person's dignity | -5,2 | 6,14 | 0,5 | | | -1,44 |
| E21 | Creating a meaningful life for the older person | -9,93 | 11,4 | 2,55 | | 0,53 | -3,6 |
| F21 | Continuously informing the older person | -16,06 | 24,67 | -5,03 | 1,62 | | -5,2 |

TABLE 10: Effects on distribution function when E21 fixed to “4” = 100%.

| | | 5 | 4 | 3 | 2 | 1 | Missing |
|-----|---|--------|-------|-------|---|---|---------|
| D21 | The older person is treated respectfully regardless of health | -20,91 | 15,54 | 4,47 | | | |
| A21 | Observing the older person's dignity | -36,37 | 20,45 | 15,91 | | | |
| B21 | Treating the older person as an adult person | -36,46 | 15,51 | 18,57 | | | |

The node with the strongest effect on the nodes within the cluster is D41. The way caregivers feel about *encourage participation* has effect on each of the nodes within Table 12.

2.6.4. Cluster VIII: Possibilities for Safety Care. Cluster VIII consists of three nodes, respectively, to *be responsible for the inner safety of older persons, to create a safe situation for the older person, and protect against mistreatment of the older person* (see Table 16).

2.6.5. Cluster IX: Possibilities to Create a Caring Communion. The final cluster, *caring communion*, contains seven nodes, which are described in Table 15. A caring communion will be established when the older person is in charge of his/her own life. In these situations, caregivers really want to fulfil the needs of the older person and thereby also show respect for the older person, that is, *show respect for the older person, be flexible, and encourage participation* (Table 17).

The potential for a caring communion to reach care relationships is dependent on the *desire to listen* to the older person, *monitoring of older person's satisfaction about care, flexibility, and respect for the older person's own decisions*. Node C11 (flexibility) has the greatest ability to affect other nodes within the cluster. Fixing node C11 level to “4,” corresponding to an improvement of the original result, the number of observations for each node increases (Table 18).

3. Discussion

In the study of ethical values and ethical manners, the Bayesian approach, represented by the use of Bayesian Belief Networks (BBNs), has been a useful method, because of the ability to compute with symbolic data. In particular, the ability to show the effects of using extended conditionalities, involving both original nodes as well as clusters of nodes,

has been a useful insight. The computing process, as enabled by the structure identification capability of BBNs, generated clusters of network structures and ended up in a total of nine clusters. Four clusters described ethical values (ethos), and five clusters explained possibilities as experienced by caregivers and how to act in an ethical manner in the daily work with the older people.

Clusters consist of a BBN of nodes (three to seven nodes per cluster), and the relation between nodes within a cluster forms the specific character of the cluster. The comprehension of clusters is therefore given by the statements, in form of conditional probabilities, within that specific BBN. We can state that the Bayesian approach had possibilities to generate clusters and underlying structural entities of relevance for the aim of the study. The structure identification capabilities enabled to find distinct dynamics within the clusters, as soon as the conditions of individual nodes were changed from the initial conditions.

Our intension was to find “what-if questions,” like “*what happens if the conditions of one or several specified nodes within a cluster are changed?*,” in order to prevent irregularities in the area of ethics. The dynamics of fixation of one or more entities to a given level can be seen in the cluster *dignity* consists of seven nodes or entities. There are small differences between the agreement levels of respective informants. About 85–94 percent of the informants totally agree with all seven statements. In Table 1, we have the distribution function for the cluster *dignity*.

Tables 1, 4, 5, and 6 represent changes between different assessment levels. We have to note that the material for the study was limited, and far-reaching conclusions cannot be made, but the results of the study point at entities possess power to change ethical ideals and manners in a remarkable way. This insight is of vital importance for the development of ethical manners in daily nursing care. Ethical values (ideals) such as integrity, dignity, safety, and caring community are embraced by the majority of respondents. However, we still have to note that cluster *dignity* has three percent ($n = 735$) of the observations at level “3” (sometimes) or lower, while within cluster *integrity* four percent ($n = 315$). Within this group of clusters, *dignity* was the only cluster which showed significant effects when the conditions for any of the nodes were changed.

Clusters describing ethical manners were the following: *closeness, distance, dignity, safety, participation, and caring communion*. Within these clusters, we can see numbers of significant effects if the conditionalities for given node were changed (Tables 9, 10, 12, and 15). Powerful negative effects on the entities probably change the opportunities for the older

TABLE 11: Cluster VII: Possibilities for participation.

| | | Distribution function for Cluster VII (percent) | | | | | |
|-----|--|---|-------|-------|------|------|---------|
| | | 5 | 4 | 3 | 2 | 1 | Missing |
| C1 | Freedom for the older person | 77,14 | 18,1 | 1,9 | | | 2,86 |
| E1 | To believe in the older person | 89,52 | 8,57 | 0,95 | | | 0,95 |
| D41 | Encourage participation | 33,43 | 42,65 | 14,45 | 6,09 | | 3,38 |
| A41 | Promote continuity and preservation in the care process as a whole | 23,81 | 42,86 | 24,76 | 3,81 | 0,95 | 3,81 |
| F41 | Being emphatic and sharing the moods with the older person | 29,5 | 40 | 24,76 | 2,86 | | 2,86 |
| A11 | Support resources of the older person | 15,24 | 57,14 | 24,76 | 1,9 | | 0,95 |
| G41 | Being humble while caring for the older person | 42,8 | 36,84 | 13,52 | 5,36 | | 1,47 |

TABLE 12: Effects on distribution function when D41 fixed to “3” = 100%.

| | | 5 | 4 | 3 | 2 | 1 | Missing |
|-----|--|--------|-------|-------|-------|-------|---------|
| C1 | Freedom for the older person | -4,4 | 6,36 | -1,14 | | | -0,82 |
| E1 | To believe in the older person | -0,48 | 1,33 | -0,6 | | | -0,27 |
| A41 | Promote continuity and preservation in the care process | -2,61 | 13,24 | -7,06 | -0,57 | -0,52 | -2,48 |
| F41 | Being emphatic and sharing the moods with the older person | -10,87 | 6,27 | 7,99 | -1,79 | | -1,57 |
| A11 | Support resources of the older person | -3,31 | -0,17 | 2,87 | 0,46 | | 0,15 |
| G41 | Being humble while caring for the older person | -1,9 | -2,43 | 3,61 | 1,57 | | -0,83 |

TABLE 13: Effects on distribution function when A41 fixed to “4” = 100%.

| | | 5 | 4 | 3 | 2 | 1 | Missing |
|-----|--|------|-------|--------|-------|---|---------|
| D41 | Encourage participation | -6,8 | 13,18 | -2,87 | -2,16 | | -1,36 |
| G41 | Being humble while caring for the older person | 5,26 | 6,57 | -10,89 | -0,04 | | -0,9 |

TABLE 14: Effects on distribution function when F41 fixed to “4” = 100%.

| | | 5 | 4 | 3 | 2 | 1 | Missing |
|-----|--|--------|------|-------|-------|---|---------|
| D41 | Encourage participation | -2,73 | 6,68 | 1,68 | -4,18 | | -1,47 |
| A11 | Support resources of the older person | -10,48 | 9,53 | -0,95 | 0,48 | | 1,43 |
| G41 | Being humble while caring for the older person | 6,08 | 5,55 | -6,69 | -4,41 | | -0,52 |

person to have good ethical care. However, earlier studies highlight the importance to develop an ethical culture at the unit. Without ethical discussions and models, the way to act in ethically critical situations, each caregiver acts in their own way, and it will not be possible to guarantee the older person ethical good care, because the quality of the care is depending on the individual caregiver's attitudes and manners [27, 28]. Promoting ethical good care is the responsibility of the whole work team.

Caregivers participating in the study indeed approved ethos as it was expressed in the clusters of dignity, community, security, and integrity. A certain dynamics can be seen within cluster dignity, that is, coherence between the statement and the opinion of the informant. This was clear particularly in relation to basic care needs and in care situations with older people who generally suffer from frailty and increasing degree of cognitive decline.

The study shows that the caregivers' attitudes to entities like compassion and mercy, moments of calm, respect, and compliance with the wishes and needs of the older person

are of major importance in maintaining a dignified care. The perception and comprehension of the older person, as a person who lived a rich and meaningful life and where disease and illness changed that person's life, is important for the formation of ethical manner. Positive approaches to the older person, seeing the person behind the illness and suffering, are basic prerequisites for ethical manners in the daily care. Based on earlier research and results from this study, we know that the view of the older person and knowledge about ageing processes are some of the most important entities in the daily care of older persons [29–31]. Respect and dignity of the older person were also in earlier research proven to constitute one of the major caring challenges. The views of the older person link to numerous ethical challenges, and therefore greater attention should be considered in both education and training of caregivers.

Tornstam shows in his theory of gerotranscendence how the ageing process results in a value of displacement in the elderly [29, 32]. The older persons experience about their life as meaningful, having the right to control their lives

TABLE 15: Effects on distribution function when A11 fixed to “4” = 100%.

| | | 5 | 4 | 3 | 2 | 1 | Missing |
|-----|---|-------|-------|-------|-------|---|---------|
| D41 | Encourage participation | −0,65 | −0,13 | 0,31 | 0,04 | | 0,42 |
| F41 | Being emphatic and sharing the moods with the older | −4,5 | 6,67 | −4,76 | 0,47 | | 2,14 |
| G41 | Being humble while caring for the older person | 0,12 | 0,48 | −0,86 | −0,26 | | 0,54 |

TABLE 16: Cluster VIII: possibilities for safety care.

| | | Distribution function for Cluster VIII (percent) | | | | | |
|-----|---|--|------|------|-----|-----|---------|
| | | 5 | 4 | 3 | 2 | 1 | Missing |
| D31 | Be responsible for the inner safety of older person | 66,7 | 26,6 | 3,8 | | | 2,9 |
| A31 | To create a safe situation for the older person | 30,0 | 47,0 | 17,0 | 3,0 | | 3,0 |
| B31 | Protect against mistreatment of the older person | 51,0 | 26,7 | 13,0 | 4,0 | 0,6 | 4,7 |

TABLE 17: Cluster IX: possibilities for caring communion.

| | | Distribution function for Cluster IX (percent) | | | | | |
|-------|--|--|------|------|------|------|---------|
| | | 5 | 4 | 3 | 2 | 1 | Missing |
| B11 | Person-centred care | 30,2 | 49,7 | 17,7 | | | 2,4 |
| E41 | The desire to listen to the older person | 41,9 | 44,8 | 9,5 | | | 3,8 |
| D11 | Monitoring of older person's satisfaction about care | 56,2 | 29,5 | 11,4 | 0,9 | | 1,9 |
| B41 | True presences | 44,8 | 42,9 | 9,5 | | | 2,9 |
| C11 | Flexibility | 4,6 | 45,9 | 41,7 | 6,5 | | 1,5 |
| C41 | Encourage participation | 41 | 41,9 | 13,3 | 1 | | 2,9 |
| F/E11 | Respect for the older person's own decisions | 3,8 | 13,3 | 34,3 | 29,5 | 10,5 | 8,6 |

TABLE 18: Effects on distribution function when C11 “4” = 100%.

| | | 5 | 4 | 3 | 2 | 1 | Missing |
|-------|--|-------|-------|--------|-------|------|---------|
| B11 | Person-centred care | 5,57 | −0,57 | −3,48 | | | −1,52 |
| E41 | Listen to the older person | 2,21 | −1,15 | −1,25 | | | 4,01 |
| D11 | Monitoring of older person's satisfaction about care | 14,17 | −3,01 | −10,58 | −0,55 | | |
| B41 | True presences | 5,09 | 0,25 | −5,82 | | | 1,47 |
| C41 | Encourage participation | −1,54 | 0,5 | 2,03 | −0,05 | | −0,92 |
| F/E11 | Respect for the older person's own decisions | −3,55 | −6,64 | 1,7 | 9,32 | 4,13 | −4,97 |

regardless of the health and functional status, and feeling respected is important entity for the experience of dignity. Wadensten and Carlsson [31, 33, 34] showed in their studies of the previous phenomena, that the caregivers did not properly perceive and comprehend the older person. In order to guarantee ethical care for the elderly, it seems likely that the view of the elderly needs to be changed, and the elderly should be seen as an adult with her own life to live, regardless of health or illness. Wadensten and Carlsson [31, 33] state that caregivers have not observed the value shifts as Tornstam [29] explained in his study.

Earlier research and findings [8–10, 12, 20] from this study are consistent with each other. Opportunities for unethical manners and ethical challenges are in previous research described in a rather context dependent and descriptive way, and often without prospective and prognostic aspects. This

study aims to include foresightedness and to highlight the probable effects on and prospects of ethical care. If we do not take these negative attitudes seriously, as we can see in the findings section, good ethical care will be at risk.

On the basis of the present study, we can only state that there are differences in caregivers attitudes. Some caregivers felt it was “almost” or “every time” possible to act in an ethical manner, while others did not feel they had sufficient possibilities to act ethically. The reasons for those possibilities being limited is not confirmed in the present study but appear in some previous research [13, 35, 36]. In addition to the views of the elderly and knowledge about the ageing process, we should further include observations about situations where the total resources are not in balance to meet the needs of the elderly [37, 38]. Different opinions within the care unit about the caregivers ability to provide care in accordance with

the ideals, related to good ethical care, moral anxiety, and guilt, are further circumstances [36] to be considered beyond the scope of this study.

This stress is clearly related to the quality of care. The situation can become very serious. Earlier research reports about serious medical errors and even death, illness, indifference, and arrogance [35–37].

We cannot overlook leader's responsibilities, as leadership sets the norms and upholds a culture [39]. The leaders support and create conditions for caregivers to act in accordance with the collective agreements about ethical good care, but they also explicitly provide and disseminate the ethical care criteria for and within the organisation. Leaders also take questions about resource allocation seriously, by creating human and material conditions for caregivers to act in accordance with their ethical ideals [39].

This study is unique in its kind, both concerning the selected approach and methodological questions. BBNs have not been used significantly in nursing research, nor are there any studies that examine the ethical possibilities with focus on the probable effects upon changing conditions.

An important point to make is that results must be understood given the translation of symbolic data from numbers to logical concepts and statements. Ethical ideals and ethical manners are phenomena that indeed make no sense to be explained exclusively by numeric data. The data represented and presented in the study are seen as symbolic data and appear, for example, as clusters of ethical ideals and attitudes which obtain their special character of the entities (nodes) and forms the network within the cluster. The character of a given cluster depends on the explanation given the cluster. The nine clusters within the study are interpreted from caring science perspective [7, 24–26] and earlier research about ethical questions in the daily work with the older person. In view of this transformation from numeric to statements, we have thus moved along the path *from statistics to logic*.

4. Conclusion

The study has opened up new opportunities to prevent services from becoming increasingly impersonal and stereotypical, and instead becoming care-based concerning ethos with ethical manners.

The nodes that describe the cluster's character may in the future not only serve as a basis for ethical discussions and decision-making, but also be starting points for caregiver's individual development.

The structure of the cluster with the underlying entities, that the study generated, seems to be an interesting development of the ISAEC instrument. The clusters with underlying nodes could be used as a framework for the continued development of instruments to identify caregiver attitudes to ethical values and ethical approach.

In summary, we can state that the study has enriched the ethical discussion and opened up new "what-if" questions. That in turn creates awareness of barriers to ethical good care.

Ethical Approval

Ethical permission for the realization of the study was provided by the Community Board of Social Care (§180/2005) for the municipality in which this study took place. Good scientific praxis in accordance with the directives of the National Advisory Board on Ethics (2002) and the Helsinki declaration (2008) has been followed.

Disclosure

The paper has been planned, written, and evaluated in close cooperation with the other authors.

Conflict of Interests

The authors declare that no conflict of interests exists and that no financial relationship exists to any organization.

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Research Article

Nurses' Perceptions of Their Relationships with Informal Carers in Institutional Respite Care for Older People

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The purpose of this study was to describe nurses' experiences of their collaboration and relationships with family members in institutional respite care for the elderly. The family has a particularly important role in respite care, which is an extension of care provided at home. However no published studies were found on this subject. The data were collected through qualitative interviews ($N = 22$). Content analysis of the nurses' descriptions of their collaboration with family members yielded four main categories as follows: (1) conscious ignoring, (2) attempting to understand the family's situation, (3) hinting at private family matters, and (4) being a friend. The results lend support to earlier findings which emphasize the complexity of relationships between nurses and family carers. A novel finding here is that these relationships may also develop into friendships. Greater emphasis must be placed on primary nursing so that the nurse and informal carer can build up a genuine relationship of trust. If periods of respite care are to help older people and their families to manage independently, it is imperative that nurses have the opportunity to visit their patients at home.

1. Introduction

Supporting family carers is a globally recognized objective in elderly care [1]. Nevertheless the development of appropriate services has been a relatively slow process, and the main focus in those services is still on the needs of the care recipient [2].

Finland's population is ageing faster than in any other country in the European Union; latest figures [3] put the number of people aged 65 or over at 941 041, or 17.5 % of the population. The target set in the national old age policy strategy is that 91-92% of the population over 75 should be able to live at home either independently or with the support of social and health care services and/or family members. One of the major elements of the national old age strategy is a support mechanism for informal care, which is governed in Finland by legislation (937/2005). Support is granted mainly on grounds of need for help and on how closely the carer is tied to care provision. Support for informal care includes both a cash benefit (min. 364, max. 729 euros per month) and the right to take three days off each month. The sums earmarked for the benefit vary from one municipality to

the next depending on their financial situation, which means that informal carers in different parts of the country are not in an equal position. Informal care is of great importance to the national economy. Estimates for 2006 suggest that without the contribution of carers, an extra 11,600 persons would have needed permanent institutional care. Nevertheless the number of carers receiving government support remains much smaller than the number of those who receive no support at all [4]. The costs of cutting public services for older people have often been borne by informal caregivers [5].

Institutional respite care services are provided via both the public and private sector. The cost of service use to the client is the same in either case, and most of the cost is borne by the state. In both cases services are governed by provincial authorities. Most smaller municipalities in the country have chosen to organize respite care as part of their regular long-term health care services, but many larger towns often have dedicated wards in connection with nursing homes.

Carers argue that their frail family members need more services, more support and more guidance, rehabilitation, and training [6]. One of the most important forms of support

available to caregivers is respite care. If home care is to succeed and indeed if the carer is to cope with all the demands of care, it is crucial that work is stepped up to develop the range of supportive services available [5]. According to Nies [7], services should all operate in a more "joined-up manner." This will necessitate new, innovative ways of delivering services to older people. However, no reliable evidence was found that respite care delays entry to residential care or adversely affects frail older people [8].

Collaboration between nursing staff and family members in the home care of older people has recently received increasing research attention, but even so this remains a comparatively under-researched area [9]. This is true particularly in the case of short-term institutional care [10]. Furthermore, most of the work in this field has been done from the carer's point of view.

Earlier studies have shown that caregivers greatly value the opportunity to use respite care services [10–12]. They give them the opportunity for freedom and a normal life for a change and on the other hand release them from concerns about the quality of care. According to Gilmour [10], nurses played a key role in carers' decision on service use. When they had good cooperation with the nurse, carers could trust that their family member would receive proper care; this allowed them to take a break from their care relationship for the duration of respite care. Nurses, for their part, respected these carers' expertise. Caregivers wanted to have a close and personal relationship with nurses [10, 13]. Carers have been found to benefit not only from the break in care provision afforded by respite care, but the support they receive from professionals in terms of information and skills is also important to the continuity of home care [11, 12].

Revising family caregiving through an empowerment framework has been shown to guide health professionals in promoting caregiver well-being [14].

Ward-Griffin and McKeever [9] and Jeon [15] have studied the relationship between nurses working in community care and caregivers. Both found that this relationship is a learning process in which both parties learn to work together, albeit at different levels and through different stages.

Earlier research in acute hospital settings [16, 17] and nursing homes [18, 19] has shown that genuine family involvement in the nursing team is far from a matter of course. The relationship between nurse and family often remains superficial, formal and rather forced [18, 19]. One of the reasons lies in uncertainties about the allocation of powers and responsibilities [20]. The findings are consistent that nurses attach great importance to their collaboration with the patient's or client's family [21–24]. Nurses also seem to agree that family members are the primary sources of information on the patient's as well as the family's situation. The family member's role as a source of emotional and psychosocial support to the patient is also well recognized [21, 24]. On the other hand nurses seem to be less interested in the carer's own situation or in how they are coping [13, 16, 23].

A major focus for many earlier studies has been on factors that promote and hamper collaboration between the nurse and carer. One of the key requirements for close collaboration is that family members themselves take the initiative and

show an interest in working closely with nurses [10, 19]. Earlier studies have shown that the personal characteristics of both nurses and family members can both promote and hamper collaboration [25]. Hertzberg and colleagues [21] found that nurses actually try to avoid relatives who they find difficult. According to Gilmour [10] it is particularly important for nurses in short-term care to locate themselves in a secondary and supporting care giving role.

2. Materials and Methods

2.1. Aim. The study reported here is part of a research project on family nursing underway at the School of Health Sciences, University of Tampere. The aim of this study was to answer the following question: how do nurses perceive their relationships with informal carers of older people in institutional respite care?

2.2. Sample. The sample consists of 22 informants, registered nurses ($n = 3$) and practical nurses ($n = 19$), four of whom were men. The informants were employed in two nursing home units specializing in institutional respite care. Furthermore, the interviewees had completed the formal qualifications of primary nurse. After graduation the nurses had worked primarily with older patients on average for 11.5 years (range 1–30 years). Practical nurses in Finland have developed from mere auxiliary workers into health care professionals who work closely with other professionals. They hold a key position in the client-oriented care of older clients [26].

2.3. Data Collection. The research protocol for the project was submitted for approval to the National Advisory Board on Health Care Ethics in 2002. In this study the data were collected in spring 2005 in a nursing home in one of Finland's largest cities (pop. over 200,000). The nurses were informed about the ongoing research project both orally and in writing. Appointments were made with each of the 22 ($= n$) nurses and the interviews were conducted during working hours in a conference room outside the ward. The topics of the interview were formulated on the basis of earlier studies [9, 27] (Table 1). The interviews lasted from 55 to 90 minutes (mean 75 min) and they were all conducted by the same researcher. All the interviews were tape recorded and transcribed verbatim. The total research material ran up to 312 pages at 1.5 spacing.

Data collection was designed with a view to maximizing information yield, and saturation was reached after interviews with 19 nurses. However, since the final number of participants was not specified in advance [28] and all the nurses wanted to participate in the research, the interviews were continued until all of them had been interviewed.

2.4. Data Analysis. Data analysis consisted of conventional content analysis [29] (Figure 1). First, the research material was read through by one of the researchers several times in order to gain a sense of the whole. The data were then coded verbatim in order to extract key notions. In the process

TABLE 1: Topics of interviews with nurses.

| Interview themes |
|--|
| (i) Your education and experience in the nursing care of the elderly |
| (ii) Describe your interaction with informal carers |
| (a) upon admission to respite care |
| (b) during respite care |
| (c) upon discharge from respite care |
| (d) during home care |
| (iii) Describe your own thinking about working with the family of elderly patients |

of analysis the researcher made notes of her impressions, thoughts, and preliminary interpretations. A tentative coding system was created by using labels extracted directly from the text. These codes were then grouped into meaningful clusters. At this stage there were still a large number of clusters to facilitate classification. The analysis was continued by combining clusters with similar contents into subcategories, which were given appropriate labels to describe their contents. Subcategories comprising similar contents were finally combined into categories and labelled according to their contents.

2.5. Ethical Issues. The ethical principles of qualitative research that warranted attention in this study were the autonomy and beneficence of nurses. Only very few of the nurses in the sample had previous experience of research interviews and therefore it was considered important to stress to them that participation was voluntary and that all the data collected would be handled in confidence and anonymously. All interviewees were in the employ of the same organization and they also knew one another well. To minimize any risk that the interviewees might be identified, they were interviewed alternately from both wards. It is for this same reason of anonymity that the original interview excerpts quoted in this article make no reference to the respondent's gender or job position [30].

3. Results

The interviewees described their relationship with carers via four categories (Figure 2).

3.1. Conscious Ignoring. Conscious ignoring (Figure 1) in the nurse-caregiver relationship was reflected in the mutual sense that there was not enough time for interaction. Family carers did not seem to have the time to get genuinely involved in matters concerning their relative. Nurses presumed that carers were simply so exhausted that the only way they could try to cope was to skate over problems as quickly as possible. Nurses, for their part, were also extremely pressed for time in their job. Sometimes up to nine new patients were being admitted at the same time, and on top of that the previous group of patients was being discharged. Especially in the case

of regular clients it was felt that there was no point wasting precious time talking to family members. The relationship was described as a matter of routine, with communication effectively confined to asking whether there was anything new or special that the nurses needed to know (Figure 1).

“...I mean obviously the first time round it's important to explain how these things work, but when they've been here a few times things go more quickly ... all you have to do is wish them a good break.”

Conscious ignoring was also reflected in a mutual tendency of withdrawal as well as in the nurse and carer remaining strangers to each other. Nurses seemed to think that family members were withdrawn and reluctant to have any closer contact with the nurses. Some nurses said they positively loathed the idea of asking carers how things were at home; this was tantamount to prying into private matters. The nurses' tendency of withdrawal was manifested in their lack of courage to go up to the carers and talk to them. Some were reluctant in their capacity as primary nurses to assume responsibility for their patient's overall care. As a result they also developed no caring relationship with the family.

“...We also get these fast-track types in, quite clearly. The client is admitted, they leave in a fortnight's time and absolutely nothing at all happens during this period. ... [22]”

One of the strategies of consciously ignoring others was that of evasion. Nurses took the view that family members lacked the courage to approach them and speak to them. Sometimes they would slip into the patient's room without anyone even noticing. Some of the nurses admitted to their own reluctance to approach family members. Avoidance was a conscious strategy most particularly vis-à-vis demanding daughters or wives. Nurses were apprehensive when they knew a difficult family member would be visiting the ward and preferred to keep away when they did.

“... I mean we just can't do all of it, can we. I mean this wife she spent hours on end here every day and every day there was something she ... there was always something that was wrong. That's not at all amusing. Really you don't want to go, you don't want to be there when they come, if I'm completely honest to you. ... [13]”

3.2. Attempting to Understand the Family's Situation. Nurses also wanted to foster a collaborative relationship with carers by trying to understand the family's situation. This required an active interest on the part of nursing staff as well as a keen grasp of situations because carers rarely took the initiative to approach nurses. The carer did not necessarily have to say anything about their situation at home, but the nurse would simply observe their facial expressions, gestures, and the whole way they carried themselves. Nurses said they could infer much more about the family's situation from the patient's behaviour and their extraordinary caring demands

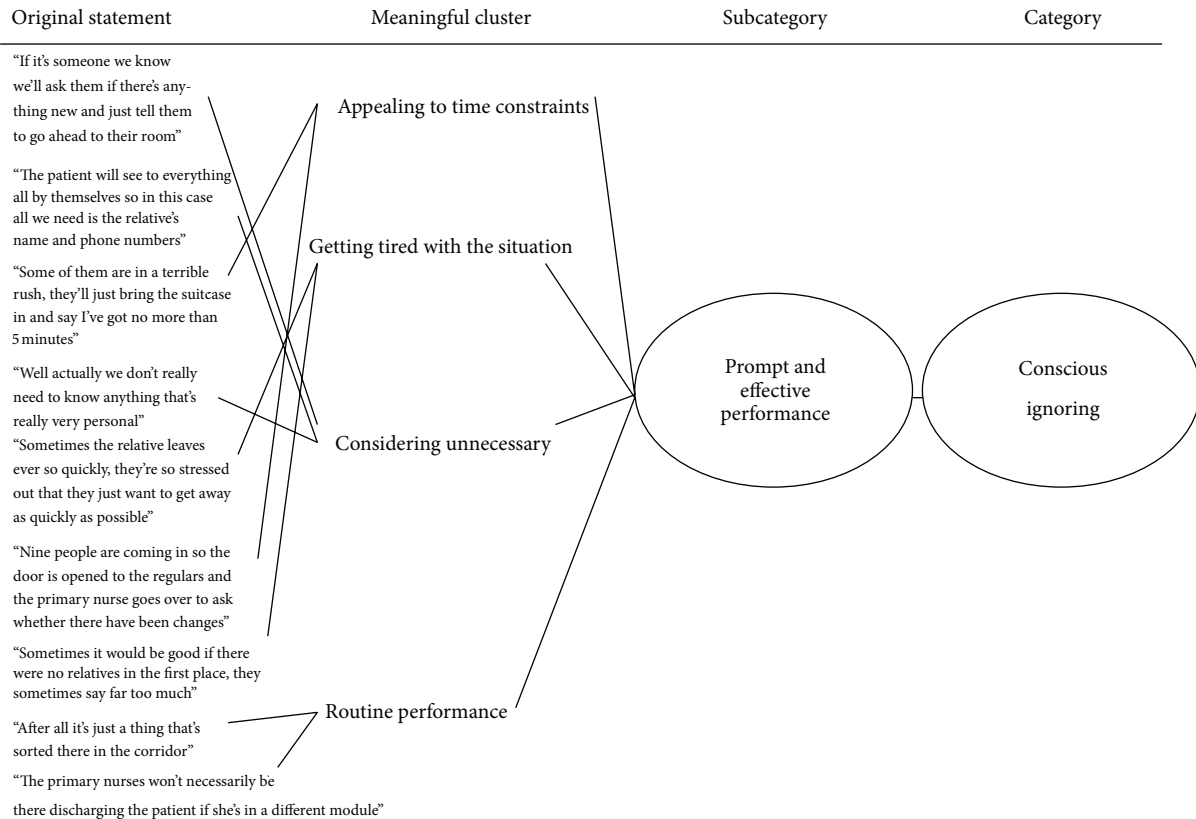


FIGURE 1: Example of category development in content analysis.

than they could from any verbal accounts. Many carers were also said to have a deeply felt need to give vent to all the pent-up emotions caused by their current situation. That, however, required a close relationship of trust and confidence, which the nurses described as being on first-name terms. In this situation nurses felt they were capable of offering support to carers.

"...I'm sure they never say it straight out that they're exhausted, ...often there's this absolutely unnecessary fuss, somehow you don't necessarily hear them say it, it's more a matter of observing their behaviour and the rest of it, seeing their fatigue and exhaustion..."

The attempt by nurses to understand the family's situation was also reflected in their seeking to come to agreement with carers on various day-to-day decisions. Both were keen to ensure the continuity of home care as well as institutional respite care. Many carers had written instructions for nurses, who had no objection to this. Nurses recognized that the carers were competent care providers. Nurses rarely gave any advice to carers, or at least they did not feel they were doing so.

"...the thing is they really have a way of organizing these things. Sometimes it's quite unbelievable, I mean without any ... well I suppose you do become a nurse of sorts if you look after your spouse at home..."

For the most part the behaviour of carers during their visits on the ward was regarded as appropriate, which helped to foster better collaboration. They helped their relatives with routine everyday activities, which made the nurses' jobs easier and was therefore gratefully accepted. Sometimes it was necessary to hold back the carer who could not see the difference between the ward and their own home. Overactive carers might delve into such jobs as reorganizing the ward's refrigerator and disturbing other patients' meals simply by making a loud presence of themselves.

"...I mean honestly this relative was absolutely impossible. She got involved in everything...every afternoon the wife appeared and began fussing about and complaining and she must have had a very hard time of it herself..."

3.3. Hinting at Private Family Matters. Hinting at private family matters was reflected in both disclosing and concealing information about family life. Sometimes family members would readily disclose even very sensitive and private information, without any sense of shame. Excessive drinking and the abuse of medication were major causes of concern for carers. Periodic admissions for respite care were often like a short detox programme, and all the carer wanted was to see the patient's human dignity restored. Both upon admission and at discharge carers were particularly concerned about how the patient would cope at home and how they themselves



FIGURE 2: Collaborative relationship between nurse and family carer in respite care for elderly patients.

would manage. According to the interviewees carers did not expect their problems to be resolved; all they wanted was someone they could trust and who would listen to them and encourage them. Hinting at private family matters required a collaborative relationship based on mutual trust, the foundations for which were created upon admission to respite care.

"...actually it's pretty important the admission situation... if it's all a bit unimpressive and you just try to get through it all quickly, then obviously the impression won't be very good..."

Sometimes nurses found themselves caught up in the middle of arguments between family members. Tact was

required especially in situations where family members were critical of each other behind each other's backs. Nurses were particularly unhappy to find themselves in situations where they were being persuaded to side with one or the other party. Many of these arguments had to do with decisions of permanent institutionalization against the patient's will. Family members would try to persuade nursing staff to support their view by constantly calling and visiting them to make their arguments. They refused to cooperate and eventually wore down all the parties.

"...it's really difficult and really annoying and really gets on your nerve and you feel you have this band around your head all the time, clamping you

from first thing in the morning, oh no here we go again with this same old... [21]"

Given the behaviour of family members on the ward, nurses said they sometimes found themselves wondering whether the patients were safe at home. Sometimes a family member would become verbally abusive against the nurse for the slightest of reasons, clearly disclosing an easily agitated temperament. Bruises and a tendency for older patients to become emotional rather too easily turned the nurses' thoughts to the possibility of abuse at home: this might include financial exploitation or general maltreatment. The nurses notified the social worker of any obvious instances of abuse. The matter was never raised with the family members or the patients themselves; this remains a firm taboo.

Many of the interviewees had visited their patient's home, either to return something that had been forgotten on the ward or to check that conditions at home were such that the patient could indeed cope. The best way to get to know the patient's family, the nurses felt, was to see how they lived at home: seeing their home told them more than any description ever could. Most nurses felt that they did not know enough about the patient's situation at home. Therefore it was impossible for them to have a very clear idea of how respite care fitted into the rest of the family's life.

"...it gives you a completely different perspective when you've been round to see for yourself... I've seen the physical environment where they live... I mean... it says nothing when you learn that they live in a block of flats. But when you've seen that flat, it says a great deal about that person..."

According to the nurses' accounts hinting at private family matters was not easy for either party. Family members concealed the real situation at home by saying nothing about their problems, and nurses did not always dare ask unless the initiative was taken by the carer. Very often hidden problems only surfaced at meetings of the multiprofessional health care team. There might have been indications of abuse, but because of the threat of disclosure family members may have decided to take the patient home early and never return. Sometimes carers also opted to say nothing about the patient's abuse of medication and excessive drinking, and these problems would only become apparent with the appearance of withdrawal symptoms, nausea, and irritability.

It was clear from the nurses' accounts that they, too, concealed things that had happened during the patient's stay. They would do so when they knew or suspected that the carer would have objected or been annoyed. Nurses respected the patient's wishes by allowing them to smoke, for example. Referring to their professional competence, nurses had a different assessment of the situation than the carer who imposed restrictions. However the disclosure of whatever family members had forbidden undermined the credibility of nurses as well as the relationship of trust between nurse and carer. Sometimes the clients themselves wanted to conceal what had happened during their stay from their relatives and insisted that the primary nurse say nothing to family members.

3.4. Being a Friend. Nurses and carers sometimes became friends who shared a mutual affection. In long-term relationships the nurse became part of the patient's family. Occasionally nurses became friends with the patient only and worried about how their friend was doing when they were at home. The death of a patient was often a heavy blow even to nurses, and they would grieve together with family members. Friendships sometimes extended beyond the patient's death. During their time off nurses might visit their clients and attend family celebrations. Friendship was also seen in patients or carers maintaining contact with the nurse during periods when they were at home. On the one hand nurses were worried about how their friendship affected their professionalism. At least initially, friendship required working as a primary nurse. Once they had become friends, nurses were reluctant to continue as the patient's primary nurse because they were wary of becoming too closely involved in the patient's and family's private life. Conflicts and disagreements between family members and patients were particularly awkward in situations in which it was thought that the nurse's professionalism may be compromised.

"...I've been trying to say this to these primary nurses that when they've been with these long-term patients who've been here for a long time... that they remember the limits, that you can't keep it up if you get involved.... You also get these situations where you have to be on the client's side, if you really become a friend with family members, you have to be able to retain your professionalism..."

4. Discussion

The nurses' descriptions of their cooperation with carers resulted in four main categories: conscious ignoring, attempting to understand the family's situation, hinting at private family matters, and being a friend. The results describe tendencies in the collaborative relationship, rather than distinct strategies adopted by the nurses. It was thus possible for a single nurse to show aspects of several categories in his or her dealings with the carer.

One important goal of respite care nurses is to support the carers, which requires both parties' willingness to work together [15]. According to the results obtained in this study, nurses sometimes even consciously ignored carers, making collaboration impossible. It was particularly difficult or even impossible for nurses to focus on the carers during the patients' admittance into respite care, as they were busy with the leaving patients. In these situations nurses sometimes chose to handle the interaction as fast as possible, especially if they were already familiar with the patient. While this is understandable, such behavior does not encourage carers to talk to the nurses on a nonsuperficial level. They have no chance to talk about the events of the home care or share their wishes about the contents of the respite period. Because of this, it can be difficult for carers to trust the patient will receive quality care. According to earlier studies [10, 13], carers do wish to have a close and personal relationship with the nurses.

One reason for the failure to form a collaborative relationship may be the idea that the family's personal issues do not concern the respite care staff, even when they are related to the patient. The staff focuses solely on the patient's physical needs, failing to provide holistic care or consider the carer's needs. Respite periods and home periods follow each other as separate phases in the family's life. Nurses who value their profession must seek to understand the reasons behind carers' dissatisfaction rather than avoiding them and situations they find difficult. Carers' despair and disappointment at their perceived lack of fortitude can be a reason for their dissatisfaction, which they sometimes vent at nurses. Disagreement between nurses and carers is not uncommon [20, 21]. The nurses interviewed in this study felt themselves helpless before demanding carers [21] and had no other way of handling the situation than avoiding them. Support from colleagues and facing difficult situations together is the professional way of dealing with such problems, which benefits carers as well.

However, this study also found that nurses would consciously build their collaborative relationship with carers by spending time with them alone [15, 25]. Nurses were interested in the carers' coping and tried to support them in various ways. Nurses need to be able to approach carers who do not discuss their thoughts on their own initiative. This enables them to share personal and difficult matters with the nurses. Building trust and a collaborative relationship takes time, which is why the primary nurse should not be changed. This study also found that setting and clarifying boundaries during the respite period was also a form of supporting carers, though nurses found it difficult and time-consuming. Contrary to the findings of earlier studies, nurses welcomed carers' participation in treating their patient during respite periods [19, 20].

Another form of collaboration between nurses and carers identified in this study is hinting at private family matters, which included both concealing and revealing difficult issues in the family's life. The results can be used to consider the reasons that allow or prevent carers from speaking openly [15]. According to Ashworth and Baker (2000) [11], both carers and patients require guidance, education, and advice on the use of respite care services to enable them to fully benefit from them. One reason for the concealing discussed by the nurses can simply be the carers' inability to receive proper help in dealing with the underlying causes of their problems during respite periods.

The nurses in this study found situations involving family tensions difficult, which is consistent with earlier studies [9, 10, 15, 21]. One such situation the nurses described was the patient instructing how much the nurses were allowed to tell about the patient's issues to their family. In other cases family members would try to make the nurses choose sides in family arguments. The patient's inability to cope at home and potential institutionalization, even against the patient's will, were difficult and sometimes exhausting topics to the nurses. In situations such as these, neither the nurses nor the carers should be left alone. A multiprofessional team is required to handle the matter. On the other hand, if nurses notice the patient is being mistreated, they should not leave

the issue only to other professionals such as social workers, as this leaves the family without nursing support (cf. [21]).

In cases where nurses stopped acting as the family's primary nurse after befriending them, the patient and carer often found it difficult to understand the reason for their decision. It is paradoxical that the nurse who best knows the family's situation and has won their trust should withdraw out of fear of not being able to properly perform their duties. Nurses in such situations should carefully consider if they are truly helping the family by stepping aside. It is not surprising that nurses become friends with the families they work with, as the relationship often lasts for years.

4.1. Trustworthiness. The main difficulty with the method of content analysis lies in how well the researcher succeeds in extracting meaningful categories from the data and in demonstrating how they tie in with that data [29]. The analysis is described in this article in such a way that the reader can trace its various stages.

According to Lincoln and Guba (1985) [28] credibility refers to the truthfulness of the results and depends among other things on the commitment of the researchers to the study. One of the researchers in this study has extensive experience of working with older patients as well as of the interview method used, while another has a strong background in theory building in the field of family nursing. The clearest indication of our success in achieving the trust of the informants was that they all wanted to participate in the research. Transferability refers to the applicability of the results in other, similar contexts. The informants only represented the staff of two wards specializing in respite care from Southern Finland. However, similar care is also provided in home settings as well as on ordinary nursing home wards especially in rural areas.

Dependability refers to the presence of human variation. The interview situations here were made as similar to each other as possible, since the nurses were interviewed during working hours in an environment that was familiar to them. It is possible that the time pressures on the ward adversely affected the nurses' ability to concentrate on the interview. Confirmability, as an element of reliability, means that the results are drawn from the material rather than based on the researchers' personal views.

5. Conclusions

According to our results, the following conditions are necessary for the nurse and carer to reach a collaborative relationship.

- (i) Forming a collaborative relationship requires time, which means the unit should not admit and discharge respite care patients at the same time. The focus must be on the family, rather than the organization. This allows for continuity between the care given at home and the care at the unit. Another important form of creating a collaborative relationship and understanding of the family's situation is the nurse visiting

the family at home, particularly at the beginning of the care relationship.

- (ii) Both parties require education. Information aimed at carers must include matters related to the contents of the care and their own role in influencing its quality. Nurses need to be trained in recognizing their own starting point in difficult family matters and the nurse's role in holistic professional caregiving. Group-based job supervision and support from colleagues are important methods of ensuring the nurses are able to cope at their jobs.

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Research Article

Living with Uncertainty: Older Persons' Lived Experience of Making Independent Decisions over Time

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The aim of the study was to illuminate the meaning of older persons' independent decision making concerning their daily care. Autonomy when in care is highly valued in the western world. However, research shows that autonomy can give rise to problematic issues. The complexity of independence and dependence for older people when living at home with help has also been highlighted. In Sweden, older people are increasingly expected to live at home with help from municipal home care services, and study into this aspect of care is limited. This study is a part of an ongoing project and has a qualitative life world perspective. Audiotaped narrative interviews were conducted and analysed using a phenomenological hermeneutic method. Findings revealed a main theme: "living with uncertainty as to how to relate one's own independence and dependence with regard to oneself, and others." This involves a constant process of relating to one's independence controlled by others or oneself, and adjusting one's independence and dependence with regard to oneself and others. The conclusion is that professional carers need to acknowledge the changing vulnerability of dependent older persons over time. The implication is a relational approach to autonomy beyond the traditional individualistic approach.

1. Introduction

The care of the old, with an increasing population over 60 years old, presents a challenge worldwide [1]. In Sweden municipalities are responsible for the care of the old, and older people are now increasingly expected to live at home aided by municipal home help services. As a consequence older people's care needs have increased as well as the workload for professional carers [2]. Older people apply for support, and the help available includes laundry, cleaning, shopping, personal care, meals, and emergency alarms. Care managers assess their needs according to the Social Service Act, which requires that people's right to self-determination and integrity should be respected [3].

Autonomy when in care is highly valued in the western world and involves people's right to make their own choices without involving others [4–6]. Nevertheless, in the care of

the old this individualistic approach to autonomy is problematic due to their dependence on others in their everyday lives [4, 7–9]. However, Sandman [6] argues that it is important to recognize that people value their autonomy differently. Further, it is therefore important to distinguish between different aspects of autonomy, that is, self-determination, freedom, desire fulfilment, and independence. The most central aspect is considered self-determination and means how people make decisions in accordance with their own will. Whereas independence means how people perform or carry out decisions regardless if they decide to do it themselves or hand it over to someone else to decide. Olaison and Cedersund [10] found that in assessment meetings between care managers and older people applying for home care the focus was on fixed standard solutions based on social service practice, and older people had to negotiate within the standard solution context to make clear their individual needs.

Research into older people in need of home help and care highlights the complexity of independence and dependence. Independence for older people has both positive aspects, for example to be able to make one's own decisions, and negative aspects in terms of isolation and underestimating one's needs [11]. In a study [12] with older people of their experiences of frailty and followed over time, findings show the complexity of how they balanced between autonomy and dependence. The findings of Hammarström and Torres [13] show the complexity of older people's striving for self-determination at the same time as accepting their dependency. However, Welford et al. [14] reveals in a concept analysis of autonomy for older people in residential care that professional carers can improve older people's autonomy in caring relationships and create the opportunity for them to be involved in decision making based on their own abilities.

Studies into older people's independent decision making using municipal home help services appear to be rare. Nevertheless research shows the complexity of the balance between independence and dependence for older people in home help care. In addition the findings in Breitholtz et al. [15] study reveal that the older persons struggled for the opportunity versus resigning themselves to losing the opportunity to make their own decisions. This was further understood as the older persons are not being treated as individuals, not having their needs met, and their life situation being stressful. These findings were considered important and inspired us to further deepen the understanding of the older persons' lived experiences of making independent decisions. This study is a part of an on-going project adopting a qualitative and life world perspective [16] to illuminate the meaning of older person's independent decision making and of their professional carers to enable this. Accordingly, the focus is on the meaning of the lived experiences. The aim of this study was to illuminate the meaning of older persons' independent decision making concerning their daily care.

2. Materials and Methods

2.1. Participants. The participants were seven older persons who had been part of the project from the start and who are presented elsewhere [15]. The inclusion criteria were aged 70 or more, both men and women, being able to speak and understand Swedish, and varied levels of care needs and still living alone at home with daily help from municipal home help services. In addition they were cognitively screened prior to enrolment and before data collection for this present study according to MMSE [17], requiring a score of at least 24 out of 30. Before data collection commenced staff managers phoned the old people to ask if they were still interested in participating and being cognitively screened again. After they had been screened and given their verbal consent to continue participating they were phoned by the first author and an appointment for a second interview was set up. Participants were between 80 and 91 years old, with four from one municipality and three from another, and with one man and six women. They still lived alone at home with professional carers visiting between one to six times a day. The domestic help provided consisted of tasks such as preparing

meals, cleaning, washing up and making up beds, and care help with such matters as personal hygiene.

2.2. Data Collection. In order to deepen the meaning and understanding of the participating older persons' lived experiences of independent decision making, they were each interviewed three times in October and November 2009 and January 2010. The interviews were conducted during and after one of the participating older persons' professional carer, they were paired with, participated in an educational programme. The same [15] open-ended interview guide was used with open questions such as the following. Can you tell me what it is like when professional carers help you with your daily care? Can you tell me how you experience the opportunity to make your own decisions about your daily care when a professional carer is helping you? To deepen the understanding follow-up questions were asked such as the following. Can you tell me more about what you thought about that? Can you tell me some more about how you felt? Participants were encouraged to narrate as freely as possible about their lived experiences of making independent decisions. The interviews were conducted in the older person's homes and lasted between 40 to 65 minutes.

2.3. Data Analysis. Data analysis followed the phenomenological hermeneutic methodological stages: naïve reading, structural analysis, and comprehensive understanding with a dialectic movement between explanation and understanding [18, 19]. The three interviews with each participant were first separately transcribed and read and a first naïve understanding was formulated for each of them. Thereafter, all interviews were analysed as a whole to enable an in-depth understanding of the older persons lived experiences. A naïve understanding was formulated and guided the succeeding structural analysis. This analysis began with dividing the whole text into meaning units expressing one meaning and those were further condensed to formulate the essential meaning as briefly as possible. The condensed meaning units were then abstracted in an on-going process into sub-themes, themes and a main theme (see Table 1). They were further reflected upon with the naïve understanding in mind, in an on-going process to validate the naïve understanding. A comprehensive understanding was formulated through reflections on the interview texts, naïve understanding, main theme, themes and sub themes, the research question, authors' preunderstanding, and relevant literature to deepen the understanding [18].

2.4. Ethical Considerations. This study was approved by the Regional Ethics Committee (ref. 2008/256). Participants were informed in advance [15] that they would be paired with a professional carer, followed over time and cognitively screened again prior to their continued participation. Confidentiality was assured and an informed consent was signed and collected before the first interview. They were contacted by the staff manager before data collection for this study and asked if they still wanted to participate. This procedure was chosen primarily to obtain a declaration that the older persons receiving municipal home help service still wanted

TABLE 1: Examples of the structural analysis.

| Meaning units | Condensed meaning units | Subtheme | Theme | Main theme |
|--|---|--|---|---|
| Yes, they come with me and sometimes they have to go on their own if I am not well and I have to stay home. Well sometimes I go by myself. ... Well it is like you look forward to something at the beginning of the week then you go shopping. But I am not allowed to really. ... I am happy with the way it is. ... Well I go along with the way things are. Well I wait for Friday as if it is something special | To not be able to go out and shop for oneself and to be dependent on professional carers help imply that one's wishes will be limited. It does not feel good but it will work | Neglecting one's own need to allow for the needs of others | Adjusting one's own independence and dependence with regard to oneself and others | Living with uncertainty as to how to relate one's own independence and dependence with regard to oneself and others |
| If the professional carer does not have the time then she tells me. Then I have to understand that she will have to rush off somewhere else. There could be other people lying on the floor needing help to get up, so that is what comes first | To accept that the professional carer says that she does not have the time to help. There may be other caretakers who need her help urgently which she must attend to first | | | |
| Well there are some who are a little bit faster but she is rarely here but that doesn't really matter. Well they sometimes are in a hurry like that. ... It is not often they take their time. It is different; all girls are different and do different things. Well you know who is who and who is better than the other but you never say anything because each of them does things their way. Well I would not do it that way, but we all are different I get the help I should have anyway. ... | All professional carers are different; some are more stressed than others. One does not always agree with their ideas. To accept as long as they do what they should | Withholding one's thoughts | | |
| Usually you can tell by looking at people what they want themselves and what they would think if you get too close or like that. If you ask someone about a personal matter they will tell you, if they do not like it, of course they would. But it happens so rarely so I cannot recall, you really notice on people how open they are. Well then you avoid that of course, remembering those you can't talk to anyhow or about anything. Others I can talk to about anything as if they were one's daughter coming to visit | Some professional carer is more difficult to get contact with than others. It is important to know who want to open or distance themselves. To learn gradually wish of them, it is possible to talk to or not | | | |

to participate and that their health had not declined since the first interview was conducted in spring 2009.

3. Findings

3.1. Naïve Understanding. Making independent decisions is conditional on the other people involved in the organization. One's life is a part of that organization that includes all the people being involved, and one tries to understand how one fits in. To make it smoother for all persons involved, one complies and sets aside one's own needs and wishes. One's own ability to express needs and wishes are limited by the

fact that the decisions and regulations within the organization are outside one's own control and that of professional carers. To expect the arrival of a particular professional carer is both joyful when they show up but also disappointing if they do not. The endless wait for them to come limits one's own freedom or induces feelings of fear of being left alone and not being able to take care of oneself in one's own home. Deciding for oneself is to have the opportunity to participate in one's own care and a trustful relationship with professional carers, giving and taking with each other. The wish is to be independent and professional carers are an extended arm no matter who provides the help. Yet one's own dependency

TABLE 2: Subthemes, themes, and main theme.

| Sub-themes | Theme | Main theme |
|--|---|--|
| Relying on others to manage one's life | One's independence lies in the hands of others | Living with uncertainty as to how to relate to independence and dependence with regard to oneself and others |
| Deciding for oneself is beyond one's reach | | |
| Waiting for others to come | | |
| Deciding for oneself when to become involved | One's independence lies in one's own hands | |
| Managing oneself with professional carers as an extended arm | | |
| Handing over the decisions to others | | |
| Giving and taking in the relationship with professional carers | | |
| Neglecting one's own needs to allow for the needs of others | Adjusting one's own independence and dependence with regard to oneself and others | |
| Withholding one's thoughts | | |

changes over time and it feels safe to hand over responsibility to a professional carer to decide about one's daily care. It may involve an implicit struggle and a wish that the responsibility should rest in their hands, but it is not taken for granted that they acknowledge one's spoken or unspoken needs. The ability to receive help from one's surroundings makes one feel less dependent on one's professional carers. Not wanting to be a bother to one's relatives makes oneself feel more dependent on professional carers.

3.2. Structural Analysis. The findings from the structural analysis are presented in a main theme following themes and their subthemes (see Table 2).

3.2.1. Living with Uncertainty as to How to Relate One's Own Independence and Dependence with regard to Oneself and Others. Making independent decisions in daily care over a period of time involves "Living with uncertainty as to how to relate one's own independence and dependence with regard to oneself and others." Being aware of one's own vulnerability to dependence on others and still wanting to be independent presents a life-changing situation, as one tries to comprehend one's everyday life. This comprehension involves relating to one's own independence and dependence on others, but this raises uncertainty because one's dependence changes over time and is affected by circumstances within the organizations and professional carers' working conditions. It makes it complicated and one has to live with uncertainty every day since one never knows who is going to come. Although one has a particular professional carer who provides special attention over a period of time, there is still no guarantee that one's needs and wishes will be fulfilled, and one is still uncertain when this person will come. Being uncertain makes one dependent on others such as relatives and other people in

the organization, and one tries to comprehend how to make it work for all persons involved.

3.2.2. One's Independence Lies in the Hands of Others. When *relying on others to manage one's life* one has to strive for independence with the help of others. Feeling independent depends on what help one may get from professional carers and close friends and family. On the one hand being able to get help from relatives, friends, or the private sector facilitates a decreased independence on one's professional carers. On the other hand, one's desire to not burden relatives induces an increased dependence on professional carers.

Well, I just told her that we only can have one lamp on in the bathroom. Directly she says, but then I can help you I can fix that for you she said. Well at that time I had already had my breakfast so she didn't have to make any breakfast for me. Afterwards when I had taken the shower and my foot was fixed, well she reckoned she had the time to fix it for me. But otherwise I never ask for help like that, because I have my children who help me with many things. I usually try to let them fix things like this for me. But otherwise it is no problem for me to ask for help with things and I get it done.

Independence is relying on the willingness of others to help, and this is something one tries to handle to organize life in the best interest of all persons involved.

Deciding for oneself is beyond one's reach when others are making decisions about one's needs and without having the opportunity to express one's wishes due to the time-pressured working of professional carers. One has no opportunity to arrange their work schedules, and one therefore, has to accept

that one may have to meet different people every time. One's own needs and wishes are not fulfilled when one has to follow their work schedules without the opportunity to express what would be appropriate for oneself.

Well they just bring what I want, but I do not like though that they are not allowed to heat in a pot nor in a frying pan. They are only allowed to heat food up in the microwave. It becomes quite monotonous. They are not allowed to fry eggs or anything like that. There is a lot that you would like to have that can only be fried, but they are not allowed to do that. Well, it is just that you have to have stuff that goes in the microwave and it's not good, an omelette would be nice. No, they are not allowed under any circumstances. Well, it would feel like a relief because I could shop differently than I do now.

Care managers assess one's needs and professional carers have to follow their decisions with no opportunity for oneself or them to change these. Having to ask care managers for support on every single help need complicates everyday life.

Waiting for others to come not knowing at what time professional carers will arrive limits one's freedom to live in accordance with one's life plans. It prevents one from making plans for everyday life, when you are sitting and waiting for them. Even though one can leave home it is not good knowing someone is there while one is out. Not knowing when they show up can also induce a feeling of limited freedom and of being disturbed trying to live one's life, but also a fear of being abandoned and not being able to take care of oneself.

... It is tough very very tough, well phew. ... That is really the worst part of it, being in the bed well, because then I am vulnerable. That is why I tell them every time when they leave, make sure the door is locked. Because it would be awful if someone broke in, well there would be absolutely nothing you could do. ... ugh. ...

Expecting and waiting for a particular carer that one trusts is a joyful experience, but disappointing if they do not turn up. One just waits and gets ready for someone in particular to come who can fulfil one's wishes and needs.

3.2.3. One's Independence Lies in One's Own Hands. Deciding for oneself when to become involved and having the opportunity to decide, when expressing one's wishes for encouraging and responsive professional carers, is good. It is also good having control over situations, knowing the best way to carry out chores for one's own personal well-being, and making one's own decisions in line with one's wishes when one has different alternatives to choose from. Not being restricted in one's own private home allows one to be free to decide.

... I do not want anything more on the table than this, one newspaper, perhaps a crossword and then the medicine that is what I want, and those pens as well. They do not care a bit, and say that my table is a mess, they never do care. But, I just tell

them, I want this stuff, that's it. But no one has ever said something like that, like someone has said do not have it this way, put it this way or that way instead. No they couldn't do that. ...

Arriving at the best solutions with professional carers allows one to decide. When they have time to listen to one's wishes it enables one to decide for oneself in cooperation with them, like being asked if there is something more one needs help with or feeling free to ask for more help.

When managing oneself with professional carers as an extended arm, although being dependent, the help given infuses a feeling of independence. It does not matter which one of them turns up since they are all equal. One can take care of oneself, just having them as an extended arm performing chores one is not capable of alone.

... I do not see any difference between the girls, they do exactly what I tell them. They just stand next to me watching when I step into the shower, all of them do. Then when I sit there washing, which I want to do myself, they leave and make up the bed. Then I just call out and tell them to help me wash my back, which they do. Then they leave and do whatever they have to do, like washing the dishes. I do not know what they are doing since it is only washing the dishes and making the bed they are supposed to do in the morning. Well, it feels good, I just call out and tell them to come.

Receiving help is just like doing it oneself, seeing professional carers as an extended arm. It is oneself who has control over the situation and one either tells them what to do or they already know. Sometimes nothing needs to be said, perhaps just a brief chat, and just get help with daily chores, and then they can leave.

Handing over the decisions to others when one's independence changes over time feels reassuring, although the wish is to be as independent as possible. To be as independent as possible yet dependent in any given situation when one has a professional carer standing by as support is the ideal. It is easier to be offered help by those who take the initiative. When the body fails to perform as it should it feels safe to hand over the responsibility to a reliable professional carer who knows exactly where one's belongings are.

Well, it was like this morning when she went into the closet in the hallway and found my pillowcases, which the others couldn't find because I did not know where I had put them. Consequently they were put on a shelf a little bit higher up were they couldn't find them. Now it turned out that the one who had taken care of the laundry and put it away had put it in another place. But she picked it out. Well it is my home, but I do not look after it all on my own, since we are so happy together so she can do whatever she wants here. She knows how to put the clothes away, and she does it without me asking her. If I want a particular pair of trousers she knows in which closet to look and she picks them out for me.

One needs to be aware of one's varying vulnerability in life, and one's ability to take care of oneself differs from time to time. In a changing life situation, it feels reassuring to be cared for by a professional carer one can trust, to remind oneself of one's value as a human being.

Giving and taking in the relationship with professional carers when one has a mutual relationship with them increases the opportunities to decide for oneself. It feels good to have contact with those one can discuss one's personal interests with. To get help from those who encourage one to manage things infuses confidence and one feels more independent. A mutual and trusting relationship takes time to develop and one needs to be devoted to.

... Of course she has learned because she has been here so many times with me in different situations. We do not only talk about how she helps me but we have private chats as well. How life goes for her and how life has been for me, so there is a very good communication between us. Well it seems quite natural together with her. ...

To give and take in the relationship is comforting and to feel respect for one another shows a willingness to make it easier for each other. Being persuaded for one's own good by a professional carer one trusts makes it easier rather than more difficult to fulfil one's wishes.

3.2.4. Adjusting One's Own Independence and Dependence with regard to Oneself and Others. Neglecting one's own need to allow for the needs of others when one sees and hears professional carers in a hurry and knowing that there are other caretakers in more need of their attention and care is also a situation to consider. One must also realise what they are authorized to do and allow for this when trying to persuade oneself to manage, as long as one gets help with the most urgent chores.

No, but I see by looking at them that they are busy. No, but then I think it may be why I do not ask for help. No, I don't because if I need help with something it may not be so urgent. If it is, I ask them and then they help me. But otherwise you can just see by looking at the different way they react.

When feeling a sense of loyalty towards professional carers and other caretakers one's own needs are not so important compared to theirs. When seeing that they are stressed one feels that one does not want to bother them and accept the fact that there is no time. Although some small talk with them would be appreciated one still has no expectations and in some instances they are not even allowed to sit down and talk.

Withholding one's thoughts how the professional carers perform their task implies a struggle taking place. One wants professional carers to understand, but even though one's own needs and wishes are not fulfilled one still says nothing. If they do things without asking it may be difficult to sort it out afterwards. It is hard correcting their mistakes while it is easier just to let it go even though one is not happy about it.

It is bad, when for example, they have done the laundry and hung up the clothes which have been in the washing machine; they never ask where to put it, they just put it anywhere. Then I do not know where it is. I do not know if it is me being stupid, but I do not want to push them too much either. Well, I think that I can correct it later.

One observes the professional carers and their different ways of working while some of them take their time others just rush around and then leave. One goes along with it and has thoughts of being nice and gentle and hoping to get one's own needs and wishes fulfilled. One tries to adjust to their personalities and adopt what one thinks is an appropriate approach. This is something one gradually finds strategies for.

4. Comprehensive Understanding and Reflections

The findings with the same group of older persons [15] revealed that they struggled for the opportunity versus resigning themselves to losing the opportunity to make their own decisions. In this present study, the findings reveal a changed understanding of older persons' independent decision making as a life situation involving living with uncertainty over time. Older persons are aware of their own vulnerability and dependence but still want to be independent. They try to comprehend everyday life and this involves a movement, a dynamic process over time changing from day to day which makes them more vulnerable. Ricœur et al. [20] states that the starting point for reflection is via objectives and opens up the world for humans to acknowledge their needs and desires and what is lacking. It opens up as a sign to offer for others to recognize in mutuality even in the isolation of suffering (pages 18-19). In the present study the findings reveal that older persons adjusting own independence and dependence with regard to oneself and others, implying that there may be a struggle in wanting professional carers to understand their needs. This is further understood as an "implicit struggle" means that the old open up and invite professional carers to enter into a mutual understanding, wanting them to recognize their exposed situation along with their suffering. Accordingly when the professional carers fail to acknowledge this invitation and their needs it makes the older persons vulnerable.

As patients become more dependent increased attention is needed to enhance their well-being [21]. Autonomy is highly valued in the western care context [4-6]. Sandman [6] suggests that it is important to distinguish between four different aspects of autonomy as they can be valued differently by people, and there is no easy norm to follow. The central aspect, *self-determination*, means how people decide and act in accordance with their own will and thus make decisions. *Freedom* is an aspect of having different valuable alternatives to choose from, while *desire fulfilment* is an aspect of actual outcomes of decisions. *Independence* is an aspect of involvement and accomplishment to do things themselves. When the old have to relate to when their independence lies in the hands

of others they have reduced self-determination, freedom, desire fulfilment and independence due to internal and external organizational circumstances. On the other hand, when independence lies in their own hands they have the opportunity to be involved and to have freedom, desire fulfilment, and independence. Older persons' dependency changes over time like circumstances in organizations and professional carers working conditions. This complicates everyday life and they have to live with uncertainty since they never know how things will be. Research shows that the ageing process makes things one is surrounded by in the home be seen in a different way and that routines provide continuity for older persons to live independently [22]. Accordingly attention needs to be paid to how older persons perceive everyday life and the importance of continuity for them. In a study, findings show that frail older people living at home with help experienced little support for their efforts in their everyday life [23]. Agich [4] argues that dependent older people have to accept being placed in the hands of others, relying on others to recognize their needs and help them. In this study, it was found that when older persons' independence lies in the hands of others it was interpreted as professional carers not recognizing their everyday life, which results in a routinized care. They also adjust to their independence and dependence, are aware of their dependency, and accept the situation. This is in line with the findings of Anderberg and Berglund [24] who found that when communication failed between the old and professional carers in nursing homes the old hid their vulnerability in order to be accepted. Ricœur et al. [20] point out that it is human limitations that make man fallible and fragility provides the opportunity for evil to arise (page 146). When autonomy is so highly valued in today's society it is easy to say that dependency is negative. Instead perhaps, the focus should change to help vulnerable older people and see their dependence as something human. Professional carers should acknowledge older peoples' changing vulnerability in everyday care and not just focus on independence and respect for self-determination. However, findings reveal that mutual caring relationships increase the opportunities for older persons to decide in accordance with their own needs, to be free to decide whether or not they want to hand over to professional carers to decide for them, or to decide for themselves or together with their carers. Nevertheless they are still uncertain because they never know when they will arrive. Dependence becomes accepted if patients feel free to be dependent in a mutual understanding with nurses [25]. This underlines a care with a person-centered perspective [26] and a change from an individualistic approach on autonomy towards a relational to focus on interdependence [4, 9, 27] to enable shared-decision making [28]. This relational perspective could be useful for professional carers to help vulnerable older people in caring encounters [29] to make their own decisions [6].

5. Methodological Considerations

In a life world perspective, it is important to have varied characteristics and experience amongst the participants

[16] which was achieved. Participants were interviewed three times each and data material was therefore considered rich and enabled a deepened understanding. First interview texts were transcribed and read separately for each participant (three interviews each) and a first naïve understanding was formulated. Thereafter, all interviews were analysed as a whole to enable an in-depth understanding of older persons' lived experiences over time. Lindseth and Norberg (2004) stress that interpretations have different meanings and there is not only one single truth possible. The meaning in this study of older persons lived experiences is one of the conceivable meanings, found by the authors as most useful. The findings in this study present knowledge that creates a foundation for other groups of older people dependent on help, if the reader decontextualizes the interpretation into their own context [18].

6. Conclusions and Implications for Practice

Professional carers have to acknowledge that the life situation of older persons involves an existence of living with uncertainty over time as to how they relate to their own independence and dependence as regards themselves and others. Older persons are aware of their dependence but still want to be independent. It is suggested that one should focus on seeing older persons as interdependent in the caring encounter through a relational approach on autonomy, that it is important to help dependent older persons and to acknowledge their changing vulnerability over time. Respect for older people's right to self-determination should not just be a norm to be followed at the risk of leaving them to fend for themselves. There is a need to pay attention to continuity and the routines essential for older persons, in order to understand their everyday lives when they are being cared for by municipal home help services. The implications for practice are a care of the old which focuses on a relational approach on autonomy beyond the traditional individualistic and a person-centered practice. It makes it easier for older people to have a professional carer they trust which acknowledges their vulnerability and that their independence and dependency changes over time. Further research is needed on how professional carers can improve older people's independent decision making in the relationship through a relational approach to autonomy focusing on interdependence.

Conflict of Interests

The authors declare that there is no conflict of interests.

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